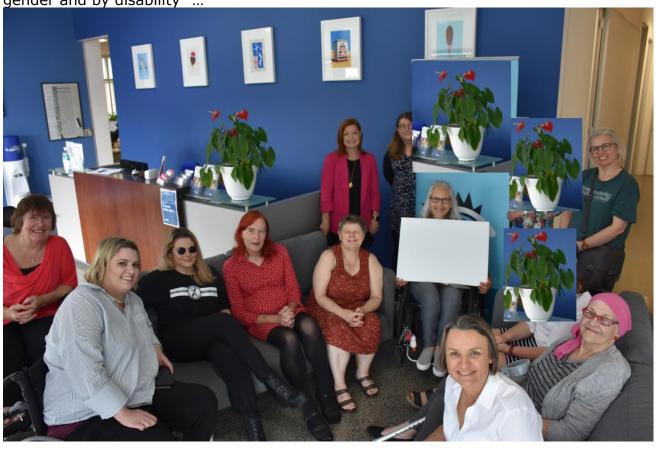


## DWF Report-zzzz CONFERENCE on DISABILITY: Creating a level playing field for ALL women.

#### Paula Tesoriero: said

On creating a level playing field one of the biggest challenges ..."is actually knowing how uneven the field is to begin with and how big the bumps are along the way" ... ..." a solution that we need to look at is ensuring that data can be desegregated by gender and by disability" ...



DWF and zzzz members, Drake Medox's staff and allies.

### **Disabled Women's Forum Conference Report**

#### Creating a level playing field for ALL women.

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#### Extract from: Far From the Tree by Andrew Soloman

... "There is something ironic in prejudice against the disabled and their families, because their plight might befall anybody. Straight men are unlikely to wake up gay one morning, and white children don't become black; but any of us could be disabled in an instant" ... "Worldwide, some 550 million people are disabled. The disability-rights scholar Tobin Siebers has written, "The cycle of life runs in actuality from disability to temporary ability back to disability, and that only if you are among the most fortunate." ...

... "The able-bodied can be generous narcissists: they eagerly bestow what they feel good about giving without considering how it will be received. Conversely, the social model of disability demands that society modify the way business is done to empower people with disabilities, and we make such adjustments only when lawmakers accept that life can be painful for those who live at the margins. Patronizing gestures can be justly scorned, but increased empathy is often a precondition of political acceptance and an engine of reform. Many disabled people say that the social disapprobation they experience is much more burdensome than the disability from which they suffer, maintaining simultaneously that they suffer only because society treats them badly, and that they have unique experiences that set them apart from the world—that they are eminently special and in no way different" ...

**Equal treatment** 

**Equitable treatment** 

Removing the systemic barrier



Or... I don't want equality or equity that makes me part of a society built on the abuse & violence that reinforces systemic discrimination. (fence is removed but it is men only, always some marginalised groups struggling for respect, inclusion & resources. Tokenism is part of tactics that control us and turn us against each other). I could turn my back on that kind of society and its tokenism and create a new society, one founded on co-operation, peace, balance & love.

#### TL; DR



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# Able people,

## shut the

up

and listen.....

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DWF are grateful to ZZZZ for the opportunity to create and present the conference disabled women envisioned, planned and despite the time constraints and stresses involved, together with the support of many allies, created and successfully presented our vision; the Conference on Disability: Creating a level playing field for ALL women. Thank you, one and all.

# A SPECIAL THANK YOU TO GAY BARTON, GENERAL MANAGER DRAKE MEDOX

In appreciation of funds offered to DWF to provide NZSL Interpreters.

We are grateful for the generous offer of financial support that enabled an accessible conference

## ZZZZ /DWF Conference on Disability: Creating a level playing field for ALL women.

#### **Introduction:**

ZZZZ -NZ ( zzzz ), is a Non-Governmental Organisation (NGO) in Special Consultative Status with the United Nations Economic and Social Council (UN ECOSOC) since 2010.

Disability-based discrimination plus gender-based discrimination double the difficulties and stress faced by disabled women. 24% of New Zealanders are disabled, 89% of these are adults; 50% of the adult disability population are women; Maori women experience higher rates of disability than non-Maori. Disabled women, regardless of ethnicity and age encounter discrimination, marginalisation and exclusion in all areas of their lives - this is more severe for Maori than non-Maori. Addressing and redressing all these issues is urgent. Ref:

http://www.un.org/disabilities/default.asp?id=150

..." The adoption of the international Convention on the Rights of Persons with Disabilities however has been unsatisfactory in New Zealand. Throughout all areas that touch the lives of the disabled, progress has been tempered by legislative, policy and funding flaws that do not truly implement the convention nor consider or understand the real needs of the community" ... (The Coalition, 2017)

DWF (Disabled Women's Forum), is an informal group established for disabled women, by Sue Sherrard, under the umbrella of CCS Disability Action. Prior to technology, meetings were Auckland-centric. Social media platforms like Facebook and Zoom have created a national forum.

The primary goal of this conference for ZZZZ Committee representatives of DWF were threefold:

Part 1: To create a national discussion on disabled women's issues. To invite ALL women to listen to our individual and collective voices on the impact of Discrimination/Ableism.

Part 2: To use the voices of the only people who can know and understand the lived experience of those issues ... disabled women ... to state the solutions WE, disabled women, want implemented, going forward.

Part 3: For disabled women (only), to meet and discuss at an informal DWF meeting, the next steps forward as an NGO to strengthen our collective political voice.

The primary goal of the non-disabled women on the ZZZZ committee was to be the best allies they were able to be, in supporting the DWF committee representatives conference vision.

ZZZZ present national conferences and NGO Reports on issues that advance the human rights of women through the United Nations CEDAW (Convention for the Elimination of Discrimination Against Women) and Beijing Platform for Action. ZZZZ -NZ is a committee of women created to report on the effectiveness of women's human rights in Aotearoa.

Until the last decade, representation of many of the marginalized women's groups, including disabled women, was missing from most of the women's NGOs in Aotearoa. In 2021, despite 24% of the population identifying as disabled in the last census, there is 0% (zero) visible disabled women/people in Parliament and 0% politicians who identify as disabled. There is no Ministry of Disabled People as there are for other marginalised populations, e.g., Maori, Pasifika and Women (*Update: October 2021 new Ministry of & by Disabled people announced*)

Government meetings organized to hear the voice of disabled people have larger numbers of non-disabled service providers and family members, who dominate discussions on what disabled people need and want. The Medical (discriminatory) Model of Disability prevails in NZ. Their priority is funding. Disabled women/people priorities are respect, dignity, safety, accessibility and inclusion.

A survey DWF did amongst disabled women some years ago said the number one social issue for disabled women, by far, was the violence and abuse targeted against us. This has not changed. The abuse and violence and the lack of access to services!

Despite Aotearoa NZ signing and ratifying the CRPD (Convention for the Rights of Persons with Disabilities) in 2008, the Medical Model of Disability, not the Social/Human Rights Model, still dominates legislation, policy and planning, e.g., the Health & Disability Act. Despite the combined voices of disabled women/people saying disability is not part of health, disability continues to be perceived as a health issue in Aotearoa. Instead of yet another physical difference the cycle of systemic discrimination uses to raise us to fear difference/each other.

In 2018, the government updated the Domestic Violence Act. The new Family Violence Act continues to exclude us, the change of name alone (removing domestic violence) excludes the variety of domestic households many of us live in, however it does now acknowledge that support staff can be intimate members of our domestic households.

It would be even better if government stopped using inappropriate, disempowering language such as "carers' and "vulnerable" etc. Language is not only powerful it is power and is used to disempower and marginalise communities of people to promote the power, control and economies of other groups of people. Our societies have created multi-billion-dollar industries globally on the backs of disabled people since the advent of industrialization.

The language of abuse/violence, including institutionalization, systemic discrimination and the social hierarchies of capitalism, marginalise and exclude disabled people from social access and participation. This continues on a daily basis for disabled women. zzzz Patterson-Lima, a non-disabled woman on the ZZZZ committee, could hear and understand, so approached three of the women on the committee who are DWF representatives or members. She asked if she could champion a conference for disabled women.

#### Joint press release by zzzz and Disabled Women's Forum

https://www.scoop.co.nz/stories/AK2011/S00623/conference-on-disability-creating-a-level-playing-field-for-all-women-in-aotearoa-nz.htm

#### **Conception of the ZZZZ Conference**

The Committee of ZZZZ see the annual conference and seminars as being part of their objectives to support and develop women's human rights in the NZ community. ZZZZ are creative and proactive in offering support to many marginalized groups within NZ.

DWF had two representatives on the ZZZZ committee. Maori Women's Welfare League co-opted a disabled member onto the committee at that time and another committee member representing trans women's issues, is severely hearing impaired, all DWF members. The conception of the conference began with zzzz, as mentioned above and the manifestation began when zzzz approached the disabled women and asked to champion the proposal to the committee.

With only two months till the conference proposed date, amidst the covid 19 pandemic of 2020, disabled women hesitated and then, as we do, jumped headlong from the frying pan into the fire. Why? Well, we know these opportunities, to have our voices and issues heard nationally, are few and far between.

With great enthusiasm and excitement, we watched zzzz staunchly support her idea, amongst other women and their ideas, hold out and finally succeed. The minutes for ZZZZ 's meeting of 6<sup>th</sup> October 2020, record for prosperity an allocation of up to \$1500; when the ZZZZ national conference was changed from conference on women and the digital age, to the conference for disabled women, thanks to zzzz being very clear her time, energy and support were going into making sure the voices of disabled women were heard ... As the ally she is, zzzz offered from the beginning to organise the technology for an online conference and meetings. We quickly organised a national meeting of any interested disabled women to discuss the way forward.

Then we had to stop, take a breath and regroup. With less than two months, the thought was just how do organisations create a conference, regardless of its focus. We would need at least a year to do what everyone suggested and work thru the issues that arose. We had two months, to create a national online zoom conference. We decided, the representatives on that committee, to choose a theme, (Solutions to long standing problems we want Government to implement and why ... that is, create a level playing field), create an agenda and together with the support of committee, members and allies, plan the steps to implement the conference agenda to an interested audience.

Sounds simple right! Many said it was not possible, especially the vision of two panels and involving politicians to speak and listen to our voices. As you know, we made the impossible ... possible. Next, we will talk about how we made it happen.

Some of the senior advocates for disabled women, who had spent decades working for disable women's human rights, felt that ableism was too entrenched and working with women's groups would create further disappointment. This was a very understandable attitude. The Conference organisers were more confident and proceeded against this warning. For this reason, one of the priorities of this report is to highlight the dynamics of discrimination, in particular ableism, to give awareness of everyday, unaware attitudes and actions ... then we can be the change we want to see.



#### **DWF Conference Objectives**

"Recognizing that disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal barriers that hinders their full and effective participation in society on an equal basis with others."

Source: United Nations Convention on the Rights of Persons With Disabilities 2006

Disability is not something individuals have. IT IS SOMETHING DONE TO THEM, BY OTHERS, ON A DAILY BASIS.

It is discrimination.

- 1. Understanding Systemic Discrimination, Intersectionality, Disability and Ableism and the impact on disabled women.
- 2. Effective-Affective communication: To be effective it must be affective. Thinking leads to thoughts, leads to attitudes, leads to behaviour. Rational or irrational behaviour and communication depends on how affect impacts on the physiological body and the language/communication we convey physically, be it words spoken or written, tone, body language etc.
- 3. Solutions to political issues provided by disabled women's voices, be listened to and acted on politically.

DWF wanted to present the 2020 Conference in a way that would/could include as many disabled women as possible, from all around NZ. Given that transport and accommodation costs are often greater for disabled people and their financial resources are lower than average, economic barriers to taking part are often very challenging.

The wide range of communication abilities also take more organization to support, than a conference that only aims to include non-disabled women. At the time the Covid-19 virus was resulting in a risk that lockdowns might be necessary at any moment. This left audio-visual conferencing as the only option that could operate through any lockdown that might be imposed. ZZZZ offered the use of the ZZZZ ZOOM account and this was accepted with appreciation. This also allowed for recording of the Conference, so that people with communication/language differences, that couldn't be accommodated during the Conference, would be able to watch it afterwards, in their own time. As for women who were unable to participate at the time of the Conference.

The potential culture clash between DWF and ZZZZ , in essence is similar to the cultural clashes that have faced ZZZZ and women's organisations nationally and internationally, as they include marginalised women was initially a non-issue as the conference and its agenda was the responsibility of the DWF representatives and the members.

These culture clashes, from DWF's point of view, are those that we face in our relationships with Government, medical profession, social agencies and all non-disabled women throughout everyday of our lives.; that all marginalised groups deal with in social systems like ours, founded of systemic discrimination, intersectionality and the power and control built into it. We must expect this, because it is ALWAYS there and our organisations need to build in ways of educating, listening and supporting each other. After all it is the core, the heart of our work together and pretending it's not happening, hurts us and prevents effective human rights progress.

Against a CEDAW/Human Rights background, it might be thought that these cultural differences would be easily managed and have little impact? The human reality is that few non-disabled women understand the breadth and depth of these issues, especially ableism, in the sense of being able to safely and constructively, manage issues as they arise during a joint campaign, under a moderate to high degree of pressure.

Few non-disabled women understand themselves well enough, in terms of their ability to handle the issues of discrimination targeted against disabled women and their roles in reinforcing that discrimination. Much less do they understand and connect this discrimination to the intersectionality of identities and discrimination that they face in their own lives. This lack of full understanding often carries with it, a disproportionate amount of fear, which can then manifest itself as communications barriers.

Equally, few disabled women understand themselves well enough, in terms of their ability to handle the issues of disability and discrimination that we face every-day in our own lives among non-abled women. This lack of full understanding of discrimination, internalised oppression and intersectionality, often carries with it a disproportionate amount of frustration and invalidation, which again manifests itself as communications barriers.

An audio-visual conference medium appeared the ideal solution in this environment where lockdowns were an ever-present risk. However relatively few NZers are familiar with this medium, particularly when many of the issues are affective. When working with participants, many who have unhealed, unresolved trauma/hurts those everyday situations can trigger, issues that can be acted out, creating "drama" that can hi-jack the process. It is often

necessary to run the proceedings with a tight time plan, to prevent derailment of the continuity.

Providing appropriate support to participants who are located remotely is also a challenge. The Conference was aiming at communication of affect, so was running very close to the emotional limits of some participants. In a similar way, it was running close to the emotional limits of non-disabled participants, who know they are part of the process of ablism, with the unhealed sub/unconscious pain, fear and guilt attached. It is this fear that makes us "switch off" and brings up either denial or "what about me". The other side of the coin is fear can bring out behaviours of power over, control, superiority and belief disabled women cannot do it themselves.

This is just a few of the attitudes and actions that manifest in ableism. There are many more, many marginalised groups share. Part of the reason for this is Colonialism, (it's attitudes and actions), the partner of Capitalism, (one goes with the historical development of the other), is built into systemic discrimination and intersectionality. It is time we outline and discuss these processes and heal the hurts that go together with the systemic discrimination installed within us from before we were born. In the intergenerational trauma of the ancestors, we are of, to the immediate instillation of the binary system the instant we come into the physical world and all the other "isms" that accompany that.

The facility for recording of the Conference, allows viewers to watch as many times as they want, to understand more fully what was being said and process in their own time. In the conception of the conference, it was ableism, what it looks like, and the dynamics of the process, that interaction between the person who is receiving the discrimination and the person doing the discrimination that we primarily wanted to convey, in the conference and in the conference report. The impact of ableism and intersectionality on disabled women especially.

However, we know it will never stop if we cannot address the impact on non-disabled women and why ableism happens. If we stay "comfortable" we will never address the issues of discrimination and the processes of why the personal is political .... both negative and positive, Hence the importance of the Speak-Out Panel first, ... the personal voice, followed by the Political Panel, ... the collective/community voice.

Another major objective was to draw attention to solutions, especially Safeguarding of disabled women and lead to improvements in actual education, policy, protection, services and well-being. Non-disabled women have access to making complaints to the Health and Disability Commissioner, which is well placed to drive resolution and protect the safety of the complainant. Disabled women have the same access, but the H&DC is poorly placed to protect disabled women targeted for abuse and discrimination, for example forensic accounting inspections. It acts too slowly to meet the needs and protect disabled women.

It has less impact on the Disability Service Providers, due to the DHBs not exercising active monitoring, not employing disabled disability advocates and not funding the costs to have alternative specialised care arrangements available at short notice.

#### Disability Service Provision Sector: Relationship with Disabled People.

"Simple, everyday ableist language can hurt others, and while there's more of an awareness now, people with disabilities are still invisible in society," ... "The key to people being more sensitive with their language is education. Don't hate the person who doesn't know – educate them." (Huhana Hickey 2021).

Disability Service Provision is a multi-billion-dollar industry built on the backs of disabled people. Just one of the Kyriarchal Systems that reinforce and perpetuate systemic discrimination, including ablism. Kyriarchal systems use kyriarchal logic, the irrational beliefs and attitudes taught as "normal" within systemic discrimination, to create the attitudes and actions a discriminatory system uses to control populations.

There are many different disability service providers within NZ. They operate from the outdated Medical Model of Disability that preceded the Social/Human Rights Model that the United Nations legislated in 2006 and Aotearoa NZ signed and agreed to implement in 2008. Nineteen years later we are still waiting for the Social/Human Rights Model of disability to be implemented in Aotearoa NZ.

Disabled women feel less than optimally supported by these organizations. Many of the organizations have existed for over 50 years, predating the

Social/Human Rights Model of Disability. The organizations have been slow to incorporate the Social Model of Disability into their culture and methods of operation. We suspect most service providers have never read or understood the international laws NZ is signatory to, including the CRPD (Convention for the Rights of Persons with Disabilities).

Relevant to disabled women is CEDAW, 1979 (Convention for the Elimination of Discrimination Against Women), CERD (Convention for the Elimination of All Forms of Racial Discrimination) 1966, ICESCR 1966 (International Covenant on Economic, Social and Cultural Rights, ICCPR (International Covenant for Civil and Political Rights 1966, CAT (Convention Against Torture and Other Cruel, Inhumane or Degrading Treatment or Punishment) 1984, CRC (Convention for the Rights of Children) the 1995, CPRMWF, (Convention for the Protection of Migrant Workers and their Families) 1990. All international legal agreements covered in the above conventions and covenants are important human rights agreements integral to the intersectionality of some of the disabled women of Aotearoa.

The question remains, why are governments globally invested financially in United Nations agreements that protect business and trade, finances, economies and especially the global industrial military complex and not in the human rights of the peoples who make up their populations. Disabled women have been devalued from the moment the Industrialization began. Institutions and our modern-day Capitalist/Colonialism form of systemic discrimination evolved when this era of Patriarchal history unfolded. This was the birth of Ablism, when physical difference was divided into self-named able-bodied people (Ables) and other named disabled people. In reality, a disabled woman is a woman who is dis-abled by other women/people, whose beliefs, attitudes and action create the environmental barriers that result in social exclusion.

Today, 2021, it continues as the NZ Government funding processes continue to emphasise the Medical Model of Disability. In this respect, NZ lags by 2 or 3 decades behind many other major western democracies. The Social Model of Disability supports individual and collective human rights, the Medical Model does not. The Social Model understands systemic discrimination is the problem and outlines how to stop the discrimination and uphold human rights. The Medical Model reinforces and continues the discrimination, ignoring human rights as it chooses.

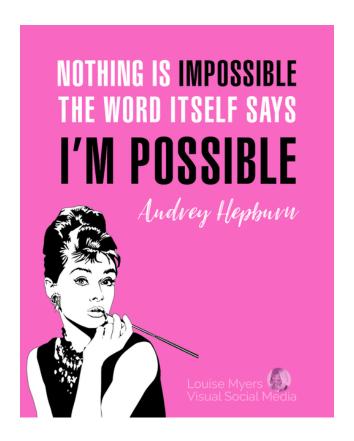
The Social Model understands that disability and health are two separate things, in the same way Women and health, Maori and health etc are separate. All women, disabled, or non-disabled can have health issues, or not. Despite the CRPD stating governments will provide funding to educated disabled people on both the CRPD and their human rights, most know nothing, or very little about either.

When you do not know your rights, under a Medical Model of Disability, you lose your voice, frightened a complaint will result in any support you are receiving being taken away from you. The support staff you hire from service provision agencies, specialist recruitment and training agencies are called in legislation "carers" within the medical model and both agency and staff placed in a position of power over disabled people who are perceived as the patient within a health system.

The lack of information, knowledge and advocacy for and by disabled clients within the medical model separates and isolates us from each other and others in a social system that excludes us in many ways, including environmental barriers that make simple daily activities inaccessible.

Understanding of the issues, implications and consequences of the Social Model of Disability is not as simple as first meets the eye. Although the Social Model of Disability is described in the CRPD, to have a reasonable understanding of issues of implementation into the lives of disabled people, is a broad and intricate area, due to the diversity of individual circumstances and relevant policies that impact. It isn't rocket science but it involves the complexities of human lives.

"Too often, our solutions have assumed a universal experience of violence and denied disabled people opportunities to report and appropriate services to keep them safe if they do," Logie says. "We have to design policies, processes and safety plans that work for all people impacted by family violence."



"Recognizing that disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal barriers that hinders their full and effective participation in society on an equal basis with others."

Source: United Nations Convention on the Rights of Persons With Disabilities 2006

Disability is not something individuals have. IT IS SOMETHING DONE TO THEM, BY OTHERS, ON A DAILY BASIS. It is discrimination.

#### **Planning of the Conference Day**

An audio-visual conference appeared the ideal solution in an environment where lockdowns were an ever-present risk. Relatively few Nzers are familiar with this medium, that non-disabled people "discovered" when covid 19 kept them at home. Given that the Conference was largely about communication of affect, how well the audio-visual format would support communication during the Conference was an aspect of concern for organizers. For that reason, Lorri set out a very tight time plan, to keep the Conference on track.

The available communications systems were changing very fast, as the Conference was being put together. We were working using moving targets! zzzz took responsibility for learning and implementing the technology required to present the conference on-line successfully.

An essential requirement in creating an accessible conference was to offer a wide range of inclusive communications options, to make it possible for disabled women across the many intersections within the disability community to attend. NZ Sign Language (NZSL) Interpreters to make the conference accessible to women in the Deaf Community was essential. Another priority was conference programmes that were accessible to different groups of women within the disabled community e.g., a screen reader programme was accessible to blind/vision impaired women, a different version was required for blind/vision impaired women who used voice technology and a different programme was required for women who identified as neurodiverse.

The ZZZZ budget, (see attached Appendix 1), was limited, \$1,500 and would not cover the cost for NZSL Interpreters. A boutique ACC service provider, Drake Medox a had begun Disability Awareness Training with DWF prior to lockdown, upskilling administration staff in understanding the Cycle of Oppression, Discrimination & Intersectionality and domestic violence (DV) in service provision. The CEO, Gaye Barton, in a meeting organisation with Lorri, hearing of the lack of accessibility to the conference for women in the deaf community, Gaye offered the financial support of Drake Medox to:

- Pay for NZSL Interpreters for the conference
- To provide a paid Drake administration staff to assist her/DWF as needed.

Thank you, Gaye and Drake Medox and thank you Gaye for the offer of future financial support from Drake Medox for disabled women/DWF.

International support, from a disabled woman who volunteered her social media expertise to create accessible conference programmes; working together with one of the organisers, a woman who is vision impaired and another woman from our neurodiverse community, to provide what was needed. We want to acknowledge Kundra and the tremendous number of hours/days/weeks volunteered to research, collaborate, create and trial the three accessible programmes she and the organisers involved, created from scratch. Thank you

#### Kundra.

At the outset of the ZZZZ -DWF collaboration, I (Maria Claire) was concerned that the group of people putting together the DWF Conference 2020 had little experience of working together as a team, within a diverse range of experience, cultures, technology expertise and human communications styles. Working as a voluntary group made these challenges harder to face, than what they would be in a professional organization. In a professional agency, paid employment involves clearly established roles and boundaries, accountability and legislation to deal with discrimination and human rights, with unions to support and deal with employment issues as they arise.

As women, volunteering on committees we share a passion for the group's objectives. In ZZZZ , this shared passion is CEDAW, and women's human rights being put into practice. What most voluntary women's groups lack is processes to listen and learn about our differences/intersectionality and the impact the unaware attitudes and actions of the discrimination we inflict on each other during normal everyday communications. In the case of disabled women, Ablism!

Overt ablism only became a problem during conference planning after the first month of the 2 months we had to organise the conference. The first month disabled women were given the opportunity to control and create a conference on a topic and format of their choice. Overall, our impression was the committee expected something simple due to the time constraints. However, this did not match the vision of the disabled women on the committee, a small group whose passion for a level playing field between ALL women and leaving no-one behind, made the impossible seem possible. We believed if you envision it, you can create it. We worked tirelessly that first month to find and engage women with visible and invisible disabilities, disabled women who identified as disabled and those who still "pass".

Part one of the conference was a crucial first step. The individual voices of disabled women that represented the intersectional diversity of the disabled women's community. Non-disabled women can recognise the attitudes and voices of ablism in comments overheard, such as ... "It doesn't matter if you miss the first part of the conference" ... "The Speak-Out Panel is not important" ... and similar sentences/thoughts. The Speak-Out Panel represented the voices of many different women with lived experience of many different disabilities and other intersections, that added other forms of discrimination e.g., racism, agism etc, that they live with. They spoke to the different ways and impacts discrimination/ablism hurt them and their lives.

If non-disabled women cannot listen to the ways their unaware socially conditioned attitudes and actions of ablism impact on disabled women, how can they understand the process and give up the control and power over, ablism gives them? How can they listen to the collective impact of ablism discussed

during the Political Panel in Part Two of the conference? How do they learn to be the good allies of disabled women they really wish to be?

All these issues and more the DWF organisers structured the conference around. The Speak-out Panel came together with the broad intersectionality of some of the women in the disability community represented. The Political Panel needed representation from the major communities in the disability sector. The facilitator of this panel was Jan Logie. In fact, the vision for this panel was based on discussions between Jan and Lorri, while Jan was engaged in the political work of the Joint Venture Business Unit and knew the statistics re violence targeted at disabled women and the lack of support and services for them. Jan wanted to hear disabled women's thoughts, solutions and priorities.

Jan Logie was the only non-disabled woman asked to be involved in the panels. As a known, staunch ally, Jan was asked to facilitate the questions and ensuing discussions of the political session. Our objective was for the thinking and solutions provided by disabled women during the conference to be taken back into the political arena.

The Minister for Disability agreed to officially open the conference and the Minister for Protection from Family/Whanau and other Violence agreed to close Part 2 of the conference, with the Disability Human Rights Commissioner to open Part 3 of the Conference, for disabled women only. Disabled women, with the background support of a few non-disabled allies on and off the committee, had now officially put together a national conference that provided a forum for the individual and collective voices of an intersectional representation of the disabled women's community and engaged the support of politicians to open, close and facilitate parts of the conference. We had begun the process of making the impossible, possible.

The agenda had been locked in and now we had to make it happen. zzzz continued to quietly gather the information, assistance and technology needed to create an on-line conference. For the information on the technological process and planning to create an inclusive and accessible on-line conference see Appendix?

The next step in the planning process was the implementation of the above agenda. It was at this stage ablism, manifested as non-disabled women wanting to take control of the process, became an issue. Until this point DWF representatives had been left alone to create a conference as disabled women chose. From the moment zzzz championed successfully for disabled women to have a conference, she immediately handed over to us to make the decisions on what, who and how, with she and other allies to assist when asked. Until this point when the agenda, with what, who and how was decided, and locked in, discrimination and ablism was a non-issue and our allies were collaborative and supportive.

On reflection, the DWF representatives and their support systems/people, think it was because we had succeeded in making the conference big enough to engage the interest, involvement and support of Government Ministers/MPs. At the core of ablism is disabled women's invisibility and lack of ability. A myth of course yet it is how we are usually perceived and at the core of people's beliefs re disability. So, we think the fear involved in the attitudes and actions of control and power over, that discrimination, including ablism are founded on, kicked in. The colonization tactic of tokenism, commonly used to divide and conquer in systemic discrimination became an issue and no time at all to sort it out. The reality is, as women we know the Personal is Political and it is easier to face the political work than it is to face the fear we have of the personal work.

Suddenly, committee members who had previously had no time for this conference needed to be seen and heard. The closer we got to the conference date the more "drama" threatened to takeover. Non-disabled women who had been supportive of our abilities to organise and co-ordinate no longer trusted us to do it ourselves with their support. They needed to be in control. It did not help that we were all sleep deprived and stressed in the final weeks.

The DWF women's mission became keeping calm, keeping everyone on task, focused and ensuring the attempts of turning the conference planning into personal dramas, was interrupted by not engaging. It was all focus, focus, focus. In the last few days, the only way to keep the focus was to not attend unnecessary meetings and hand over the illusion of control and take background seats. At that point we did not care who was seen to be in charge, we simply wanted to make sure the show went on. All strategies discussed amongst us and implemented to ensure the show went on successfully. And it did! And it was!

Again, many thanks to zzzz . From beginning to end she believed in us, provided the opportunity and as an ally offered her digital technology expertise and her time to upgrade that expertise as required, to ensure the conference DWF wanted to present, happened and our voices on our lives and our issues were heard nationally.

The ZZZZ Committee's debriefing and conference evaluation process DWF representatives and members on the committee asked for, never eventuated. We understand the fear/terror women deal with when challenging each other on the way discrimination occurs between us. Disabled women understand discrimination is based on irrational attitudes and actions we are unaware we have and act out in the belief our behaviours are rational.

Raising the challenges in this report is an attempt to be honest versus polite. In the same way women address and challenge sexism we must step through the fear and address the many other ways discrimination is acted out between us. If we do not, we will remain abusing and hurting each other, unaware we do it, as we watch marginalised women distance themselves. It is sad and it is unnecessary, we ALL want to be great allies for each other in our political work. We can if we support and challenge each other to do the personal work, individually and collectively.

DWF are grateful to ZZZZ for the opportunity, to create and present the conference disabled women envisioned, planned and despite the time constraints and stresses involved, together with the support of our allies, DWF representatives and DWF, with the support of many allies, created and successfully presented our vision; the Conference on Disability: Creating a level playing field for ALL women. Thank you, one and all.

## zzzz , Conference on Disability: Creating a level playing field for ALL women.

#### OFFICIAL OPENING By Minister for Disabilities Carmel Sepuloni.

I warmly welcome the Minister for Disabilities, The Honourable Carmel Sepuloni to formally open today's zzzz annual conference, 2020.

Thank you, Denise for the introduction and for really opening us up very appropriately. Can I acknowledge some of the wonderful women who have brought us here today, as well as some very familiar faces. Jane Pritchard, the visionary who established this organisation, Sue Sherrard, the founder of Disabled Women's Forum, zzzz for championing diversity and inclusiveness and in particular, past president, current secretary and amazing ally, zzzz King.

Paula Tesoriero the Disability Rights Commissioner, I do believe is also part of this conference and my fellow members of parliament, Jan Logie and Marama Davidson, who I've had that privilege of working with and last but not least, zzzz Henderson.

I hear that zzzz is a member of the Pacific Woman's Watch committee as well as the young woman who suggested and championed the idea of this conference. We would not be here today without these women leading us forwards. So, thank you all for your tireless work, for everything you have done and will continue to do for the Women of Aotearoa New Zealand.

You know, today we're here to talk about a number of things, including our what is a level playing field. And can I say that as the Minister for Disability Issues, previously an Associate Minister for Pacifica, the Minister for Social Development, ACC and employment, one thing that I am very cognisant of, which I'm sure you would talk a little bit about today, is intersectionality.

And the fact that when we talk about issues that disproportionately impact on women on, we need to also be talking about the intersectional issues and where there is greater impact or disproportionate impact on women who are Maori or Pacifica and are disabled.

I'd like to acknowledge the 2020 report off the Disability Rights Commissioner. It is time now disabled people are living free from violence. The report sets the scene for the state's obligations to take all available measures towards disabled people enjoying the right to be free from violence, abuse and exploitation. We know that we have limited data on family violence, sexual violence of disabled people in New Zealand. This means that we need to rely on international research. To some extent, this research has found a consistent link between

being disabled and being subjected to violence and abuse. And even if we don't have the research, I guess that the type of data that I'm referring to anecdotally, common sense tells us and our understanding of how the world works, that this is indeed the case.

International research tells us that disabled people are at higher risk and have been subjected to both family violence and sexual violence. Disabled women are up to three times more likely to be threatened with sexual assault or to be victims of sexual abuse. Compared to non-disabled women disabled women are between 1.4 and 1.9 times more likely.

The victims of partner violence, disabled women and girls and disabled men and boys with a learning disability are at much greater risk of being subjected to family violence and sexual violence. Compared to others, the risk of disabled children being exposed to physical and sexual abuse is at least three times higher.

We understand that the forms of violence that disabled people experience can differ from forms experienced by the general population. For example, withholding a disabled persons medication or denying them access to mobility aids. Indigenous disabled women are at heightened risk of being subjected to violent and harmful pregnant practises, such a sexual abuse, domestic violence, forced sterilization and neglect.

Instead, I see, even though we don't have a lot of evidence, the New Zealand evidence that is available is consistent with these international findings. We know that disabled people are at risk of more on DME or likely to experience family violence and a wider range of context, including being abused in their own homes by the carers. Many disabled people often have a have a higher level of dependency on others to meet their daily needs. They may not be able to leave a violent situation or even report it.

It is good that the Joint Venture Business Unit, where the programme is now instigating work to better understand the needs of diverse communities, including disabled people, who are at risk of experiencing family violence or sexual violence. Two million dollars has been made available by the government to progress this important work, and I want to acknowledge the work of Paula Tesorario the Disability Rights Commissioner, the Office for Disability Issues and others who have been advocating on the importance of this wig on. I mentioned Paula in particular, because she did come to those of us that were involved in the Joint Venture.

And she put the case successfully, that more needed to be done with regards to disabled people in family violence and sexual violence. On that same note, I want to acknowledge Jan Logie for the work that she did leading the Joint Venture in the last two years. There were a number of us ministers that were involved at an agency level, but Jan had the responsibility to pull things

together, as the Undersecretary on Domestic Violence. Now she's handed that responsibility this term to the honourable Marama Davidson, and we continue.

I mean, we look forward to continuing our work. We acknowledge, as a government that we're not just working with ourselves on that. It is very important that we continue to work with the organisations and individuals that have a vested interest in making sure that we get our attempts to address family and sexual violence right. And that we acknowledge and mention all of the different groups who are impacted by family and sexual violence in New Zealand, not least of which are of course, disabled women.

And I think someone has put a comment, we also acknowledge that first and foremost we need to be talking to disabled women themselves when attempting to address the issues of family and sexual violence that impact on them.

I do also want to acknowledge that this conference is a time off opportunity. And an opportunity to help us do better. The United Nations Convention on the Elimination Off All Forms of Discrimination against Women is a cornerstone commitment for our government. The Disability Action Plan work programmes are responsive to the needs and potential of all disabled people, including Maori and Pacific women and girls.

I hope these works will improve the statistics and help level the playing field, which is what we here to talk about. I welcome the leadership taken by Pacific Woman's Watch, to bring women together, disabled women and non-disabled women. We need to hear the voices of women who are disabled. And I have great hope for what we could achieve together.

## Conference on Disability: Creating a level playing field for ALL women. (PART 1)

SPEAK-OUT PANEL: facilitated by CEO of DPA Prudence Walker.

The Speak-Out Panel is designed to address the individual impact and issues systemic discrimination, including ableism, has on the daily lives of disabled women.

**PRUDENCE**: My name is Prudence Walker. As introduced, I'm the chief executive of the Disabled Persons Assembly (DPA). But what I have just said there, is my work is human rights and the rights off disabled people. I was born in Palmerston North and I now live in Wellington, after a number of years in the South Island. It's my pleasure today to facilitate this panel on disability and to be involved in this work today.

We have six panellists today and I know that there will be great conversation that comes from that, and everything said. So, I will crack on to things. I just wanted to talk about the purpose of the panel for a start.

The purpose really, is to challenge our perceptions, beliefs and thinking around disabled woman. And what disability really is. If we're successful in doing that non-disabled woman will understand that there is nothing wrong with disabled woman. We're just different in some way. Some are short, some women are tall. Some have brown eyes and some have green.

It's the type of society that we create together that really determines who is valued and respected and who isn't. Disabled women hope after this conference you can all join us in creating a society that values and respects ALL woman. Creating a level playing field between woman is the first step.

With that, I would just like to introduce the panel before I explain a little more about the process. As I said before, we have six panel members here today.

**Fala Haulangi**, a living wage campaigner and Pacific Woman's Watch NZ committee member. Fala is, a union organiser and organises in committees as a Pacifica member, to which she has participated in campaigns for Living Wage, Equal Pay and Migrant Workers Rights. She is a board member off the Migrant Action Trust in Auckland.

**Tamara Grant,** who is the CEO and founder of Xabilities.

Tamara's a youth ambassador for disability. She lived experience of autism, dyslexia, and mental health issues. She's a passionate in creative mother who aims to transform the way disability is portrayed in New Zealand through whose social enterprise Xabilities.

**Allyson Hamblett**, artist, author of "Transgender Woman". Alison identifies as a cis-gendered artist at Maputo Studios. She's written two books about of life experiences as a person with cerebral palsy and as a trans cis-gendered woman. She wants to help create a more inclusive society that's more accepting off disabled woman and trans Woman. Trans woman just want to be accepted and able to choose gender, like the rest of us.

**Kylie Berry**, **is** a deaf woman and a domestic violence survivor. Kylies deaf and comes from a deaf speaking family. She is a solo mum and has two hearing daughters, two and three years old. She has two deaf brothers and one sister and lives in Christ Church near her whanau support system.

**Dr Rogena Sterling** is an intersex person and advocate. Also, non-binary and an intersex person who suffers issues relating to medical procedures in the past. They are a scholar and advocate who focus on human rights. They have a background in law, policy and human rights and put a human rights lens on advocacy as an advocate. They believe in understanding how intersectional experiences, including class, connect with people's life experiences. They enjoy working collaboratively with others to achieve a fair and equitable society where everyone is respected for who and how they are.

**Abigail Knight** is a young woman with Down Syndrome. Abigail lives in Auckland, and she was a recipient off the New Zealand Down Syndrome Association National Achievement Awards in 2013. She works at PhD Media, which is a large advertising company for TV, radio and Internet, located in Mt. Eden.

I'd like to just go over the oppression model briefly. While it is in the information that you have received, let's talk to that for a moment. The definition of oppression we use is the model developed by Lorri Mackness: the systemic mistreatment off one group of people by another group of people that is perpetuated and reinforced through and by social institutions such as government agencies, nuclear family, schools, churches, et cetera. (i.e., the kyriarchal system)

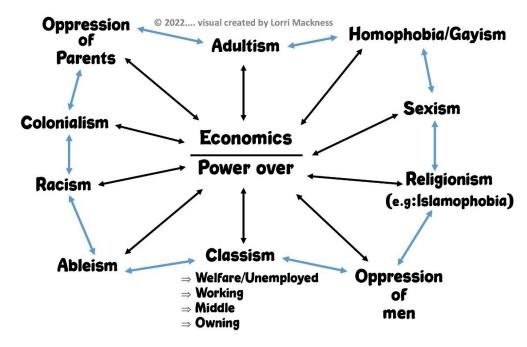
#### DEFINITION OF OPPRESSION/DISCRIMINATION AND INTERSECTIONALITY

The definition of Oppression/systemic/systematic mistreatment of one group of people, by another group of people, that is perpetuated and reinforced through/by social institutions, e.g. government, family, schools, churches, etc. (i.e., the kyriarchal system, i.e., the interconnected systems established for the purpose of discrimination, domination and submission, that uses kyriarchal [irrational] logic to install systemic discrimination as the norm in societies.)

- This systemic/systematic mistreatment and the reinforcement is almost always an unaware process. When bought to awareness it is usually accompanied by denial.
- When we look at oppression for the cycle it is, we can see that we are members of many different groups, i.e. intersectionality. In some, we are the oppressors, in others we are the oppressed. This means, in some we are abused, in some we are abusers.
- This process/cycle has been instilled/installed into us while we are much too young to fight back. We grow up thinking that the way things are, is 'normal'. We are taught to turn on each other instead of looking underneath to what is really going on that our society is based on power over/powerlessness and economics instead of humane-ness. When broken down the beliefs and behaviours that implement the process of oppression are simply a collection of individual 'distress' patterns i.e. individuals have their own unresolved hurts/experiences and the behaviours that evolve from them. When individuals come together, their individual distress patterns and beliefs become collective distress patterns and beliefs. The fact each person 'sees' things the same way reinforces the belief that 'this is how it is', this is what is 'normal' and 'natural'! What is not healed and changed in individuals and the societies they grow in, returns as ancestral memory/intergenerational trauma and the cycle continues.

#### A MODEL OF THE CYCLE

(The ism's in this cycle are just some of the communities of oppression/discrimination)



#### **INTERNALISED OPPRESSION:**

The external mistreatment only has to happen x number of times before the person internalises the message e.g., an adult telling a child, they are stupid. After x number of times the person internalises it and begins to tell themself they are stupid.... **SO** ... Oppression is the theory (Internalised). Discrimination is the attitude/beliefs and actions that implement the theory, i.e., that is the practice.

When we come together in forums such as this, then we can begin to break down some of those beliefs and behaviour's

I would now like to introduce the ground rules for the Speak-Out. As you will see in your hand out. The ground rules are that all participants and audience agree the foundation of the Speak-Out is based on the cycle of oppression. We're talking about the things said in the Speak-Out, are based on the model of discrimination, which I have just talked about.

When a panel member is answering a question, they will have about two minutes allocated to them and our timer will ring a bell when they've got 30 seconds to go. We will allow slightly more time for the deaf participant on the panel due to the use of the interpreters

At the end of the speak out, I will ask everybody who's watching in today about your next step. Either next steps as disabled woman or as allies, in the hope that it will create conversations in amongst allies and everybody that we are connected to in our organizations and businesses.

Depending on time, we may not get to every panellist for every question but we will keep an eye on the time as we go. So, without further ado, I would like to kick off with the first question.

## Q1. What do you like about being a member of the disability community?

**PRUDENCE:** Hi everybody. Fala, let's start with you.

**FALA:** Thank you, Prudence for that question. Being from Tuvalu, a woman first and foremost, I'm a Tuvaluan woman and Pacifica. We strongly believe in the collective. So, my being involved or being a member of the disability community to me it's very important because I'm learning from other woman on how we can support each other.

We faced discrimination here in our home, New Zealand, every day of our lives. So us, on our own, being a minority among the minorities in Aotearoa New Zealand, to me, it's very important that we woman, we're sisters, we stick together because we need each other. That's being a Pacifica woman here now, here in New Zealand being discriminated against every day, can you imagine being a Pacifica woman who is also disabled?

I'm not just talking about our Pacifica woman. Sitting on the migrant Action Trust as well. I have learned a lot about migrant woman and women who were refugees as well, who also need our support out there. So, to me, this is very important being a member of the disability community.

In whatever way I'm able to help I'm happy to help out as well, not only listening to each other and learning from each other, but on how we can support each other as minorities among the minorities here now in NZ.

The reality is that amongst people, being a Pacifica woman, you deal with discrimination every day. You can see that in terms of pay equity that Pacifica woman are at a lower scale when it comes to pay here. We need each other, to support each other and show we can reduce that gap of inequality and poverty in Aotearoa New Zealand.

**PRUDENCE**: Thank you for that answer. Next up we have Rogina. What do you like about being a member of the disability community?

**ROGENA:** The disability community is important because we need to be in solidarity with one another. I myself, have medical issues that have been created because off the oppression that has forced upon me at birth, the binary discrimination in society. And that's led to thing's being done to me at birth, as with many other intersex people. in many different ways, to force us into the binary of male and female.

And like many in the disability community, I see in many different means we have to stand together to make sure that, however, the oppression has been put upon us, we stand in solidarity to make sure that we can all be there to improve inclusive and participatory society for everybody and uplift everybody. So, it's important to stand together and uplift everybody.

**PRUDENCE:** Kia ora, thank you, everyone so far for your distinct responses we haven't needed to utilise the timer is yet. Next, I'd like to move to Allison Hamblett.

**ALLYSON:** It is good to be part of the disability community, trying to work together to create the kind of inclusive society that will be better for all people. I guess it's good in some ways but I feel I know what needs to be achieved in the trans community and how to achieve it but trying to find ways to build a more inclusive society for the disabled community is more complex.

**PRUDENCE:** Allyson, thank you for your response. Now, I would like to move to Kylie. Interpreters unable to see Kylie. Kylie, I'll just repeat the question for you and that is, Kylie what do you like about being a member of the disability community?

**KYLIE:** I'm a Mom and I've got two girls and before I used to live up, not in Auckland and then in Hamilton. We have moved here to Christchurch recently. I have got brothers and sisters and I'm a solo mum managing all of this. Prudence, can you just give me an example of what You're looking for? The answer. I just had a bit of the introduction. I'm just wondering, could you give me an example?

**PRUDENCE:** Yes. It's about being part of a community with other disabled people. In particular, deaf disable women and what you like about that? What you enjoy about that?

**KYLIE:** I enjoy being involved in the deaf community. Participation, you know we have fun. We have netball you know; we have different sports activities. We go out for events and movies together. So, I enjoy the whole participation and community. The feeling of being around people.

**PRUDENCE:** Thank you Kylie. Next, we will move to Tamara. What do you like about being a member of the disability community?

**TAMARA:** I have a lot of love for the disability community. I'll say a kind of a storey about before I was part of the disability community. Living with autism as a young person is really hard because there isn't really a sector that you fit in with and it leaves you alone and asking the really deep questions on am I needed? What's my purpose on Earth? That creates a riddle, a mental health toll in yourself.

And once I found the disability community, thank you. Thanks to my mother and to Yes Disability for finding those communities. I was able to give purpose to my life and also find a home, somewhere I belong because there were other people out there that we're going through the same motions of why can't I be normal and how can we get through this? And how can we make it better, more accessible too out in the world. It gave me warmth for my heart, joining the disability community and a greatness to my mental health, to my life and to where I am now.

So, there is an accessibility problem and it's invisible. The access problem is acceptance for those who are different. And that's what the disability community gave me. They gave me access to not be scared to be who I am.

**PRUDENCE:** Thanks for that Tamara. We're just going to pause for a second to make sure that we have got the right interpreters on screen before we move to the next question, Abigail, what do you like about being a member of the disability community.

**ABIGAIL:** The disability community, being a member of the community means I get this time with people I can feel comfortable being myself. I belong to disability organisations that give me the chance to make friends socially. I will find this difficult if I did not participate in organisations that support people with disabilities. We have also had opportunities for leadership. It's what I haven't had in the non-disabled community. Having these experiences, I have continued to grow in my confidence and abilities.

**PRUDENCE:** Thanks, Abigail and sorry for forgetting you. I won't forget you for the next question. Okay, so just moving into question number two and kicking off with Fala.

## Q2. What is difficult about it being a member of the disability community.

**FALA:** I think I don't really see it as being difficult. But I think from my own personal experience, I have learned a lot. That having been around the disability community they have taught me a lot. But I still believe that there are some difficulties there because I don't speak the same language. I really need to get my act together to make sure that in order for me to be able to communicate with some of them. I think it's up to us all to make sure that we really get our act together, okay?

And to be more inclusive, this world needs to really get on to this as well but I think from the things that I have been involved with, it's up to me because if I really care about the disability community then I really need to get my act together, it's up to me to do my bit to make sure that I am really communicating well with the people that I want to advocate for.

So that's how I look at it. It's the will we need, to make sure that we genuinely care about our disability community. And don't just go pretending that you care when you don't do anything about it. So that's how I look at it. From my experience so far, dealing with the union members out there, it's funny, so difficult to understand. I have to make sure that I take a very proactive step, as well in learning the language so that I am representing them 100% wherever I go. So, yeah, that's how I look at it, right?

**PRUDENCE:** Thank you, Fala. I see the Pacific Woman's Watch bell sound. No, the sound is not working, just to let panellists know that when you have 30 seconds to go and you were right on time, Fala, When you have 30 seconds to go, Pacific Woman's Watch will hold up a sign saying 30 seconds. Thank you.

Moving on to a Regina for the second question. What? Sorry. I'm just getting a little bit of feedback from my own voice. A little off putting. That's where it's

coming from. So, Regina, what is difficult about being a member of the disability community for you?

**ROGENA:** Well when we advocate for all the community, for example, the intersex community which involves many of the intersectionality's, the difficulty is we always need to remember where it's not so much a difficulty but it's an important consideration. We always need to remember. That everyone needs to be respected and included in all our advocacy, and we need to remember that people were coming into our different communities from all of the different intersectionality's and remember that each part of our advocacy must respect and include those connexions that we are, so they can participate with us.

And so, communications' that are accessible for everybody so that we can build a much broader, society that has participation for everybody from all through the disability community.

**PRUDENCE:** Thank you, Regina. Moving on. Allison just waiting for you to come upon screen there. Alison, listen, what is difficult about being a member of the disability community for you?

**ALLYSON**: It's difficult being a trans woman and a member of the disability community because of the lack of intersectionality understanding. I feel I can only raise disability issues and keep my advocacy in the trans community separate.

**PRUDENCE:** Thanks, Allyson. I'm moving to, Kylie. Please turn on your camera on Kylie? What is difficult for you about being a member of the disability community?

**KYLIE:** This question number two was a yes, that's right. Great. There has been some judgement within the community. I know that in the past I needed to buy a Christmas tree for example and people were questioning whether I could afford it. And I remember my mom. It was more difficult for me to get there because of other people. My relationship, he was older than me, and I was younger, and so I thought I was stupid.

There doesn't need to be a sort of hierarchy of people. There seems to be an unequal, equal playing field. So, some of the deaf community, it is a very small community, there's some backstabbing and gossiping and rumour spreading that happens and putting down of other people where that should just be my private life.

PRUDENCE: Thank you, Kylie. Abigail. Just a minute. There you are, Abigail.

What's difficult about being a member of the disability community?

**ABIGAIL**: I feel excluded. My friends feel excluded. Some people I know haven't been able to get one. And when we get jobs, they're usually part time like minors. Women with disabilities often do work experience, but it doesn't lead to a job participating in a forum like that. I would like to be a part of groups.

People don't see disabilities or disabilities like mine. That is challenging for me. I need time to learn and someone to help me understand the question. But I don't want to be hurt.

**PRUDENCE:** Thank you, Abigail. And the last up we have Tamara. Tamara, what is difficult for you about being a member of the disability community?

**TAMARA:** So, I had two ways to answer this question because that's a difficulty of autism, is reading questions. When I first read the question, I thought it meant like okay, as a person, why is disability hard and then it's like but they now will be talking about the community, so I've completely changed the question, but I'm happy with that. Anyway, I'll get to it.

I remember when I went to Parliament last year to a conference, an I-lead conference put on by Yes Disability and was the one person with learning disabilities there. I even fit in here on DH that really when I heard they're really hurt me to think that they didn't feel like they had a place or that it wasn't, you know, because that the disability community is where I found my place. And I would want them to be like, if you fit in anywhere.

May like these people the way had 60 young people in one room in parliament, in the parliament building, Wellington and all these people here, they know how it feels. And this is the place you know that you will fit into because they all know those tough times being different. And so, the disability sector. The community has a blindside towards invisible disabilities, which is really hard, Really and it's quite sad because there's even a lot of times where I'll go to events and they're not accessible. To, those reporters, um, it's just lighting or the music. I noticed with one of events I did when I felt a little bit lonely, I felt low on my confidence?

They don't need the invisible disability input. We went in with invisible disabilities. I was way freaked out. And so that's a day I realised no, we have to stop hiding and we know now we need to stand up and come out and be like invisible disabilities are. That we are just as important as any other disabilities. And just because we look normal doesn't mean that we don't have our struggles like anyone else. So that's something that I've found that I would like to change in the disability community. There's a lack of awareness and understanding for those who have invisible disabilities.

**PRUDENCE:** Thanks for that insight Tamara. We're going to move on to question number three. Now, in starting again with Fala.

## Q3: What do you want to never hear, see, said or experience for disabled woman ever again?

**FALA**: Once again, I will always refer to being a Pacifica woman who gets discriminated against in terms of pay as well as everything else. Every day we face it. So, sometimes as a Pacifica woman, I believe that it's a lot about women's experience. Discrimination is as I have mentioned earlier on, that it can be quite patronising at times.

You know, like when you hear people talk to our Pacifica woman, there's always that stigma; that we had done that, ... we don't know what we know... we've been instructed to do ... or we have no idea of how to do things and you know that kind of thing. So, it's a Pacifica woman's place. Don't look at us as if we are a bunch of idiots because we are not. We may look brown, we might have different accents...it doesn't make us stupid!

Another thing, the accent, like maybe because I was born and bred in the islands. I only moved here but listen because I'm not just talking about that. It's something about the rest of our Pacifica woman as well. And not only that, just because our parents, our mothers who are at the lowest paid jobs, just because they're working those jobs, don't ever make assumptions that their dumb. They're not. They're sweating your bums off for their kids, to make sure that their children will have a better future.

So please continue to treat our Pacifica woman, migrant workers also and you know, our community, our rainbow community, all of them, everyone with respect! We only have each other. Please support us. Thank you. But

Don't ever treat us as, you know, stop patronising our people because we're not your way ... And if you need us, your support is here.

**PRUDENCE:** Thank you Fala for your good role modelling. Moving next to Rogena. Rogena, what do you want to never hear, see, said or experience for any disabled woman ever again?

**ROGENA:** Okay, as an intersex person , the thing that I want to never see happen again is at birth, doctors deciding that intersex babies should be divided into male and female. And they're going to change you personally to make you fit into the binary of male or female, with many parents often very unaware of

this. They just assumed this is a medical necessity. And this can cause many medical issues, psychological issues, trauma issues for the rest of our lives. So, if there's something that needs to be done, it should be done without consent, without choice later in life.

Unless it's for life saving purposes, of which most of it is not. So, I want a society where we are all respected for who we are and who we choose to be rather than having society imposed and determined for us who they think we should be. And this is affecting millions of people around the world. So, yeah, this is really important that we love each other for who we are and not change babies/people for who they want them to be. No!

**PRUDENCE:** Yes, Ka pai Rogena Moving on to Allyson. One moment, please. Oh, I think that you're just working on your video, Allyson? Ready Allyson. What do you want to never hear, see, said or experience for disabled woman ever again?

**ALLYSON:** That trans women shouldn't be part of the community and that trans women shouldn't exist!

**PRUDENCE:** Oh, thanks, Allyson. Moving on to Kylie and just allowing a moment the interpreters. Come on screen, Kylie. What do you never want to see, hear, said or experienced for disabled woman ever again? Question number three

**KYLIE:** I just would like to talk about my experience. My next-door neighbour never, never supports us. We also have a different area organisation. Those people will believe my ex partner's story. They tried to support him. They thought that he was exposing the whole situation, where he was the actual perpetrator. It was okay for him to carry on. You know, to rape women to carry on doing this and have sex with other women.

But he told me that I need to behave myself and to go along with him and that it was just the cops making it up. For me because it's impossible, you know that I can't hear, I'm just told what to do. I don't want my children, (I've got two lovely daughters), I don't want my children to grow up learning or watching him as a role model, because when you see people oppressing others, the cycle just carries on.

And I wanted to stop that for my children, I wanted that to stop. It's actually not okay and so I decided that I would separate from him. The children are now really happy. They do not have the ongoing bully behaviour that used to happen before. They are free of it. It was just not worth it!

He wanted me to be patient and carry on with him. But I cannot. I could not.

It's better for the children. I wanted to put my children first and keep them happy because I wanted them to be safe with me. Not with a father who believed otherwise. And, you know, he had all the different problems drug, alcohol, everything that you can name. It was just not worth it.

So, I never want to see a disabled woman in that situation again. No bad influence on my children. And then I want my children to have a good future and a good life.

**PRUDENCE:** And that, I think, is special. Thank you, Kylie. Abigail, Come in Abigail,

**ABIGAIL:** For one, I would like to be known as a woman first and then with disability not a disabled woman. All equality is very important.

I have a boyfriend. And one day I would like to get married and live in our own home. They say, I can't allow this because they think I am not capable. Maybe I will need some help to live in my own home and that's okay.

I want to make decisions for myself and they centre on my plans for the future. I think this is what any woman with an intellectual disability wants. I have all sorts of opinions. My family look out for me and try to keep me safe, while still encouraging me to be independent. I want to know someone who is looking out for other women with disabilities.

**PRUDENCE:** Thanks for that Abigail. Lastly, we have Tamara. Hello? Yeah, Tamara. What do you want to never hear, see, said or experience for disabled woman ever again?

**TAMARA:** Okay, well, I have another story, a story about myself. When I was seven years old, I had a very intense passion for understanding humans. So what, how? I would have to know the chemical list, so I went very hard into studying. I learned the period table about compounds, exceptions, chemistry. And then, by the time I got into high school and you know, there's this class and it's just science. It's one class of science and I was very excited because throughout day one of starting school, to that point off starting college it had been just failure after failure after failure and I'd been told that, you know, I wouldn't be good enough.

I want to be able to bring in money. I wouldn't be able to have a family because I wouldn't be able to pass this test. So, I mean, being constantly told throughout my life that I will be nothing and that I wasn't trying hard enough.

So, I got to go to college and I'm going to show them that I've been practising chemistry since I was seven years old, I got into the class and I practised. I did all my homework and I did extra homework just in case there was some sneaky questions and then, did the test and I did not get one question right. Because with my autism, like a six-year-old, reading and writing is hard. So, I had writers but the question itself needs to be explained in detail to me, as in this process.

As in this conference, the question has to be explained really well. Usually, it's easier hearing other people answer the question to arrive on that path. So, this question, not being able to pass that class created a huge emotional turmoil because it made that one grandest hope I had for 10 years, nine years of my life saying I'm not a failure vanished and I had nothing left. I was now that failure that the peers and the teachers directly, would tell me.

So that's something I would never want to see happen to anyone else with a learning disability, because it is the most traumatic thing. It creates a huge mental health toll. I think that it's a health and safety issue in New Zealand that we standardised testing. Being marked for your intelligence by a piece of paper!! It's one of my things.

**PRUDENCE:** Yeah, thank you for that, so moving on to the final question. I'm starting again of course with Fala. (Has my video been running? Just that. My video. Okay, start my video). Now we are assuming every woman, every non-disabled woman in this audience wants to be your ally.

#### Question 4: What do you want or need from your allies?

**FALA:** I think going back, that again really, I'm here representing my Pacifica woman community that are discriminated against all the time. So, I'm saying that we really need your support to stop institutional racism, you know, discrimination and to support the weakest in terms of the equal pay.

Because if we look at the public service, Pacifica woman within that industry within the public service, have been discriminated against, in the pay gap of 21% between Pacifica and the other colleagues. So, can you imagine the public sector being able to address that? I really, really need your support on this.

As you all know, currently I am one of the champions for the Living Wage and Fair Pay Agreement. We believe those campaigns will be able to reduce inequality and inequity in our communities, especially among our Pacifica, Maori and migrant women. So, we really need your support in pushing and lobbying We need you lobbying with us, to the current government to act on these campaigns as soon as possible. In order for us to reduce poverty and inequality

in Aotearoa New Zealand, amongst our lowest paid workers. So that's what I need now. We need your voice and your support and thank you.

PRUDENCE: Thanks. Thank you. Rogena. I'm sorry.

**ROGENA:** Okay, So, first thing, many of us come into this world with enough impairments that we don't need impairments created for us. As I explained from the last question when we're born, I hope their parents, family members and greater society will accept babies/people for who they are, including being intersex, and that we can be a proud member of society.

It's important that we recognise everyone for who they are. However, they identify. For example, we have the linguistic space, social space. The legal space to be able to identify, as non-binary now. At most I have a pronoun, "they" but I don't have any other words in language to express who I am, Uncle, Aunt What? Boy girl? What? There's not even linguistic space to participate in society. So, we need linguistic space, social space, our legal space to participate in society. We need to exist in society. Period.

Understand that we don't need to create extra disabilities, including medical issues, just to fit people into the binary and we need to work together as a society to have a place where we can all grow to our potentiality. To be the best way we can be, no matter who we are. We are all valuable members of society and we need to uplift everybody to the best that they can be. That's what I want everyone in society, all our allies to remember, uplift everybody to their best potential.

**PRUDENCE:** Thank you, Regina. Next, we have Allyson just waiting again for your video. Allyson. Allyson. Assuming every woman in this audience wants to be your ally, what do you want or need from your allies

**ALLYSON:** Trans women exist and have always existed and will keep on existing. Trans women want to co-exist with cis women.

For me, I really want to be a cis woman. It's great that we have allies, but be aware that transphobia is alive and well, particularly horrific in the UK.

We need to be vigilant. We need the Human Rights Act amended, to include gender identity, gender expression and sex characteristics. We need the minimum wage exemption to be removed from our statute books and we need it easier for trans, intersex and gender diverse to update the gender on their birth certificates and retain the Declaration as to Sex for overseas born New Zealanders, including citizens by grant, permanent residents and refugees.

**PRUDENCE:** Thank you Allyson. Kylie, What do you want or need from your allies?

**KYLIE:** Organisations need to stop patronising. The society needs to stop bullying us. Well, when someone wants help, it should be readily available with options so that I can make an informed choice. What I need ought to be there if I have to use agencies like police or other organisations. Provision of sign language interpreters, a trust model so that I can choose the right interpreter to provide the right service for me. Thank you.

**PRUDENCE:** Thank you. Kylie. Abigail. What do you want or need from your allies?

**ABIGAIL:** I'd like my allies to know and show others that I am capable and like them to give me support and encouragement if I need it. I'd like them to speak to me, when it is about me not to others. So I feel validated.

**PRUDENCE:** Thank you. On to Tamara. Now again. You've got plenty of time Tamara. Assuming every woman in this audience wants to be your ally, what do you want or need from your allies?

**TAMARA:** I'm going to explain this, as during the lockdown with my difficulty of reading and English pretty much being my second language in a way because as I say, the language of autism is my first. And in this English oriented world, so with those difficulties, when lockdown happened and I went to the supermarket, everyone was lining up outside.

I didn't know what was happening. I had my child with me, I have a 3yr old son and I was like, I can't freak out. Especially in the situation when you really need food. So, I decided. Okay, I'm going to quickly run to the girl in front of the line. Just quickly ask what's happening to make sure I follow the rules and stay safe. And then, I asked the lady and she just said ... "Are you being living under a rock?" ... and she started to, just be like ... "you should just know what's happening" ... and then I explained, I'm sorry. I have autism.

I have difficulty understanding situations like that. She can just tell me, so everyone stays safe. Then after I told her I'd autism, then there was oh, I'm sorry. It's kind of like, I still wasn't being talked to as if I am human. It's just... but at least it was nicer. Then at least she explained to me how everything was going.

So, if anyone wants to help, anything I would say is keep an open mind and if you're in a position you have like a headache. Your head's feeling really tense

and you feel like the next person you talk to, you're just going to go out and just rage at them, then please make sure you think about yourself and take a time out or take a breath. Go on, get some lunch, go and have a nap because your words do affect/effect others, ... that it could ruin my day.

If I didn't have the confidence, if I was five years back down track, I wouldn't have even been able to reply. I would just be stuck in a stupor and being like oh my God, I'm freaking out okay? And that would have ruined my day. I have to find a way through level 4 lockdown, for how to do things. They are making sure that you, as in the visual, every single person, disabled or not, is in the right mental space we're creating.

The servicing is really important for the efficiency of what you're doing and also, I feel that when you're in a situation, the person with the disability needs the person who doesn't have a disability to keep an open mind and to not judge.

I've been in a situation where a lady who had muscular dystrophy came up to me and she gave me a laptop. She was like, oh, can you just solve this problem on my laptop? And I don't have that type of autism. I don't understand technology very well. So just because autism doesn't mean I'm a tech wiz, so you can't judge a book by its cover. No, there's so many different words and different ways that can offend the disability community, people from different sectors. It's like with me saying, I see you're someone with autism, that could be offensive because it's like they don't like to have autism. They could just be disconnected. I live and breathe Autism.

I don't know now if I'm being completely honest, but I feel if you talk to someone and you're being kind and considerate and you really did it and you're feeling like I'm sorry. I do not know how these pronouns work. Can you please just guide me so we can have the best conversation possible?

So, making sure you're in the right head space and just having a nice attitude behind you can really help the sector and anyone that walks through your door has a good day. I do have a book about the emotions of being different as well. I have my company Xabilities. It's about how can people reach their full potential no matter from what place. Please check out our website or social media platforms for your support and understanding of being different.

**PRUDENCE:** Tamara thank you. Well, thank you to all the panellists for the real rich thinking. They're our questions for the Speak-Out today. I'm going to just touch on a few things that stood out for me and that I captured. I know that I won't capture all of it.

The first things that really stood out for me, particularly in relation to question number one, which is what people liked about being a member of the disability community, is that reinforcement off people's identity and the authenticity and for some, giving us a purpose in knowing that we belong somewhere. Support for who I am, being myself and not being judged were some words from one of the panellists.

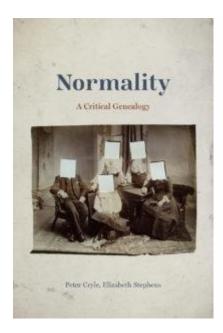
In thinking about what was difficult in the community. The things that appeared to come through for me were around the intersectionality really off our community and making sure there we include everyone. Of course, that comes with lots of diversity, lots of intersectionality. So meeting all our needs can be challenging.

I really heard from the panel members that what they didn't like was a sense of hierarchy and of the judgement and where barriers are in place. So, if we're able to acknowledge all that intersectionality, then that would lead us to be stronger as a community in general. People really wanted to just be accepted for who we are, and I think everybody wants that. In order to achieve that, we often need our identity or identities acknowledged so that we can feel confident in who we are.

Some of the thoughts around what allies could do. I think some of the words from Abigail, I think it was, stick out for me. Tell others I am capable. Make friends with me, include me and then some other thoughts were look at yourself and really think about your own behaviours and acknowledge when you might not be in the best position to interact with someone who you perceive to be different to you and not bring in those judgments and stereotypes.

And I guess that really touched on it for me as well. We are women! We usually have many things going on in our lives and many roles in that we all really need to look after ourselves. To be strong as woman in contributing to the communities that we are part off. Overall, I think that it really came through about just our being able to be ourselves. Just be accepted for who we are.

We heard various barriers and abuse in a lot of situations. Of course, that's all about the power dynamics that are at play. We just want to be accepted for who we are as woman and to be seen as women. So, thank you for that. I have great hopes for what we could achieve together.



**Normality:** A Critical Genealogy, by Peter Cryle & Elizabeth Stephens (University of Chicago Press, 2017)

"Their ambitious book pursues the emergence" ...., "and the ways in which normality has been a locus of social control. They examine the word's nearly simultaneous emergence in mathematics and medicine in the nineteenth century; and they trace its entry into popular culture in the mid-twentieth century, when it was the tool of those with commercial interests seeking to standardize mass-produced consumer goods." ...

## Conference on Disability: Creating a level playing field for ALL women. (PART 2)

"In the village of Bengkala on the Indonesian island of Bali, a hereditary strain of deafness has persisted for generations. Although it affects only a small part of the population, everyone here knows the local sign language, and deaf and hearing individuals marry without regard to either party's ability to hear. It is normal to sign and to fraternize across languages; it is in many ways normal to be deaf. The aberrant becomes a norm when it occurs with sufficient frequency in any population" ... (Andrew Soloman 2017)

#### POLITICAL PANEL facilitated by Green Party MP Jan Logie.

# The Political Panel is designed to address the collective impact and issues systemic discrimination, including ableism, has on the daily lives of disabled women.

**JAN:** Technology. Nga mihi nui kia koutou. Ko Jan Logie. And after that, I'm feeling particularly very connected to the privilege of being able to facilitate this panel discussion today. Especially with such wonderful staunch disabled women leaders. I'm going to say for myself, I don't know about you as the audience but I'm so interested to hear what they say. I'm looking forward to learning a lot from this session.

As has been mentioned, I'm also really privileged to have recently been picked to take up Mojo Mathers' mantle in the Green Party, to become our Disability Spokesperson alongside the role of being Women's Spokesperson and Child Poverty spokesperson. Obviously, there is a huge amount of overlap between the portfolios and I'm really looking forward to getting into it.

I think I've been asked to facilitate this panel because of my experience over the last three years working within government, trying to progress our response to domestic violence and sexual violence. And I've got to say, this experience has really, newly activated me to raise the voices of disabled women and I'm in the position now to be a vocal proponent within Parliament, for change.

I went into the role of the Undersecretary with several goals to transform our responses to domestic violence and sexual violence. One of them, a key one, is to shift from really ineffective 'one size fits all' response to these forms of violence, that were leaving so many women and other people without the protections that our law said they were entitled to.

So, one of the first things I did in my role was ensure that the Family Violence Legislation clarified that caregivers would be covered by the Family Violence Legislation. And we also added some examples of specific dynamics that are often experienced by people with disabilities into the definitions of the legislation. The point of that was responding in the first place, to the advocacy from women in your community over many decades, which was a long overdue change. I want to acknowledge that.

Also, to try and explicitly shift our response to family violence so that it would look for and respond to family violence in all of its forms, particularly, the forms experienced by people with disabilities. We also added dowry abuse and forced marriage with the same purpose, to make sure that it was meeting the needs of all our communities.

Putting something into law, is one thing. Changing the system to implement the law is a WHOLE other thing. I was really conscious coming into this role that the work that I've done with Mojo, and you can see in the poster behind me, was recognising the opportunities to disclose that the mainstream responses of relying on a call to the police does not work for many disabled women. We needed to create new pathways for people to be able to disclose and get help.

It was really interesting for me in starting to acknowledge that. Seeing that the public service hadn't done the policy work for us to be able to get the resources to create tailored policy responses. So, because of that, we got a small amount of funding for prevention work in marginalised communities including for disabled people. The intention from that was to be able to build relationships between our DPOs and officials who would be able to work up the case. Also, to be able to start that work on planning out how we develop those pathways for people to get help.

And I've got to be honest, that's been really slow. It's been surprising to me how hard it has been to get that moving. I thought it would be a quick, easy solution. But it turns out, it wasn't.

I'm not saying this as a criticism about the officials because they are really well-intentioned people. It is to me, a learning about the difficulties of changing the system that has strong, deep barriers that excludes the experience of disabled women.

We saw another example, when I was presenting at CEDAW and there was a question from CEDAW about whether our Family Violence Services were accessible. The initial response I had from the public service was a response saying, 'our services are accessible to all women', which is clearly, not true. Our services mainstream family violence services have not been resourced and are not, in most cases, accessible.

This showed me that either public servants, have a huge gap in their knowledge, they are not aware of the reality on the ground and/or their default was to protect the system and not the people and our public.

I've got to say, too, that when we put the changes into legislation, I think, a lot of what I saw was the system thought that putting it into law would make it happen. That they didn't need to do the work – really specific work within their own agencies - on being able to implement those protections for disabled people.

I've seen that where I've asked about those changes and what protections we are seeing for people with disabilities, because of the changes to the Family Violence Act.

I was given assurance, initially that everything was going well; it's been implemented fine. Actually, the numbers and the lack of change showed that it hasn't been implemented yet.

I really want to thank and offer my gratitude to Paula Tesoriero, our Disability Commissioner, for her intervention to put external scrutiny on this work. As Undersecretary, I set up a place to put up a foundation for change but was unable in my time to fundamentally change the practice within the public service or the community. It's clear to me that this is going to be a challenge to the new government. That they are going to need all our help to get the highlight on this issue and to shift from this default of 'one size fits all' and ensure the basic human rights of all disabled people.

I'm really committed to doing my bit and that bit starts with listening to others. So that's what this panel is about. Now I'm onto introducing this wonderful panel of smart, strategic women with lived experience of disability, who have so much insight to offer us in this work.

I'm going to introduce them all now in one group. Then, we'll just hand over to them between the questions. I'll keep the introduction short and point you to the wonderful resource that came out with the conference with more details of the huge amount of work they have done for all communities.

Also, to acknowledge apologies from Dr. Huhana Hickey, who had hoped to be in the panel but is unable to for health reasons, unfortunately. Dr. Hu is known and loved by many of us and she will be missed in today's discussion but we are very lucky to have this wonderful group.

So, first presented will be Ronelle Kitirangi Baker, who Whakapapa's back to Ngati Porou, Rongomaiwahine, Tainui and ngai hui. Ronelle has brought lived experience of muscular dystrophy to her work as a Senior Leader in the health,

disability and community sectors, as well as being a mum – the hardest job of all, I've heard.

Second presenter is Victoria Manning, our New Zealand Order of Merit holder and the General Manager of Deaf Aotearoa. She's had many years of leadership in the deaf and disability communities. Her intersectionality's, include being a deaf and disabled woman, mother of a disabled child, experience of mental distress and being a cancer survivor.

The next speaker will be Martine Abel-Williamson (QSM). She has held many governances and other leadership roles in the disability area including for the World Blind Union. She is the Auckland Kaituitui for DPA and sits on the ACC Sexual Violence Prevention Advisory Board and Family Violence and Sexual Violence Pandemic Working Group. So, thanks for that work.

Our last presenter is the New Zealand Disability Rights Commissioner, Paula Tesoriero. Her role is, and I've been a great admirer of it, to protect and promote the rights of disabled New Zealanders. She's also fabulously, a Paralympian cycling gold medallist and the Chef de Mission for our New Zealand Paralympic team, hopefully, heading to Tokyo. Our formal lawyer and very senior public servant.

So, an amazing, amazing group of women. Just to acknowledge that, similarly to the last session, the timeframe for our responses is really short and I know they hold a lot of knowledge. So, we may see this session as a taster and provoker of thinking, rather than the complete answer to everything.

The team will let all the speakers know when they have 30 seconds left. And if you are still going after that, I will reluctantly ask you to finish your sentence when the time is up.

And the audience, a reminder for you, to be able to send through questions through the different formats. And at the end of the question that I post, there will be a time for question and answer. I will be able to put forward some of the questions that have come through from our audience to get some more discussion going.

So, all of that. The first question to start our discussion today starts with Ronelle is what d
Mo you think we need to create a level playing field between all women?

## Q1. WHAT DO YOU THINK WE NEED TO CREAT A LEVEL PLAYING FIELD?

**RONELLE:** First of all, can I say, whaea Jan, Nga mihi tena koutou. I'd just like to acknowledge all of the Rangatira here in the room and tena koutou to Denise and our esteemed ministers. Thank you so much. A A privileged to be here. I want to acknowledge my colleagues and Manaakitanga, whaea Dr. Huhana Hickey. I think I was a bit of a ring-in for Hu. I'm not going to do her justice but, yeah, I do hope to do her proud being here.

Kia ora. Nga mihi nui ki a koe, for me to be here. Now, I guess for me creating a level playing field for all women is about recognizing multi-dimensional world views around what it means to be a woman, what it means to be disabled, what it means to be a disabled woman. As Abigail said it, very eloquently, in the first panel. She wants to be viewed as a woman first, and a woman with a disability second. I can totally relate to that. I guess for me, I'd like to say that, you know, Huhana has done a lot of research on the concept of whanau hoa and I guess, the first I would say is that disability is not a Maori construct. Social roles in Te Reo Maori and whanau-based approach is really what grounds me, upholding the mana of my whakapapa is the compass to which I make my decisions.

In my life, although I have an aggressive disability, I'm losing function, ability, independence, all of the time. The things that really ground me are my social roles as a daughter, sister, mother, auntie, niece, cousin and also, a wife.

So, everything I do is through those lenses. I guess, for me, that's what it is about. A level playing field is about recognizing the different world views, different constructs and valuing our social roles.

JAN: Beautifully put. Thank you. And Victoria.?

**VICTORIA:** Kia ora. Can you hear me? I will use my voice here. So, the interpreter can keep going. Thank you.

How to create a level playing field for disabled women. That's a huge question and no easy answer. And they will be lost unless you've got a pen. I'm here to give lots of perspectives, lots of ideas. There won't be one way. There will be many ways to do that.

One way I want to put forward, a very practical thing that will help, it's not a silver bullet, but it will help, and that is, I want to propose that we collectively advocate for quotas for disabled people to be employed in the public service.

You might know that there are some grounds for, well... people trying quotas, for women to be on Boards. We can do that in the government space.

Jan, you said at the beginning, in the introduction, the public service as a machine is huge. It has a huge impact on all the systems that are functioning in New Zealand society. We know those systems discriminate and create barriers

for us. So, getting disabled people into those jobs, and government which is a huge employer. Government agencies employ a huge amount of people. Getting us in there means we are more present. We are having more influence and impact.

I saw on the chat, just a few minutes ago, someone was saying that there is a very low number of accessible toilets in the public service. That is one simple thing. If we get more disabled people working there, they have to make more accessible toilets. This seems a very small thing but every day the public service is making decisions, writing policies, advise to the ministers. Everyday. Those things impact. Doesn't matter what government agency you are working in. We want disabled people to be there more.

If we have a quota, for example, saying that for every 100 people the government agency employs, 24 of those should be disabled people. Of that 24, 12 should be disabled women. Let's push for that. Let's get disabled women in those jobs. We know that we have hugely skilled disabled women in New Zealand.

I think we don't put ourselves forward enough. Sometimes, I have met so many skilled disabled people, disabled women and still I've had conversations with public who have been saying, "oh, there's not enough skilled disabled people out there". There is. There are heaps! And the people here are an example.

I do want to say lastly that, we need to put value on our skills and overcoming those barriers, discriminations and attitudes that are put in front of us every day. When we climb those barriers, we can climb under them. We knock them down and that is a skill. That is the muscle that we have developed. I think the public service should be valuing that. We bring that to your job, and you benefit.

So, quotas in the public service is one way to create a level playing field for all of us. Thank you.

**JAN:** Great. It is very clear. Thank you. Now Martine.

MARTINE: Can everybody hear me?

JAN: Yes.

**MARTINE:** Oh, excellent. If you hear a sound every now and then, it's just my computer though. So, please ignore that. It's not like other people can hear and listen in.

Thank you for this opportunity, Jan. I remember sitting next to you on the plane with my guide dog, probably about a year ago, returning from the ACC Sexual Violence Hui. I am on the Board. Although I love those meetings, they

sort of stopped because of the work of the JBBU which may be a good sign, and it may be not. But it's great to be involved today in this space.

I want to take on from what Victoria was saying and we haven't compared notes. But we've now seen years and years of disabled women being promoted over cocktail parties.

We have these social bias workshops, and anti-racist workshops and employer conference workshops and although we have more disabled women employed, and that's good, without exposure, more visibility, then we will not have an equal playing field.

I see that. Three years ago, when I was fortunate enough to be supreme winner of the Attitude awards, and people said to me, 'thank you for your contribution'. And I said, 'look, it's a collective start. So, it's not just me.' I put the word out there that if we're not at the table, we're going to be on the menu.

We need to be at the table. We need to be on the team. Whatever analogy we need to use, we've got a history of people speaking on our behalf and it's not working.

You do not see non-Maori people and non-Pacific people hopefully, speaking at government, legal and other levels, on behalf of those communities. But you still have heaps and heaps of officials and non-disabled people who are speaking on our behalf. They make decisions for disabled people but without us, without us being there. So that is what we really want to see. If we're not around to literally be involved, then we cannot be involved. There is no equity. This fight with democracy might bring equality, but it does not bring equity. Thank you.

JAN: Thank you, Martine. And Paula?

**PAULA:** Tena koutou katoa. Kia ora, Jan. Thank you for being the MC for this and thank you to zzzz for bringing this together. Jan, thank you for the acknowledgment of the report that I wrote for government. Also, I would like to acknowledge Minister Sepuloni's reference of that report earlier today.

I spoke to Marama Davidson yesterday at the White Ribbon breakfast hosted by New Zealand Police and she had also seen the report. I think what I've taken from my discussions with government thus far, with you Jan last year, Minister Sepuloni and now, Minister Davidson, I feel a very genuine and authentic desire by everybody to really make a difference for disabled women in respect of violence and abuse.

So, to answer the question before us, I think, one of the big challenges in creating a level playing field is actually knowing how uneven the field is to begin with and how big the bumps are along the way.

We are still working in New Zealand to have to segregate the data on disability as an entire population group, let alone, for disabled women, or indigenous disabled women.

We do know some things. We know that disabled women told the Human Rights Commission in 2018 that violence was their top concern. We know that we still have legislation that allows medical procedures to be conducted on disabled women without their consent. We know that disabled women fare worse in employment outcomes and incomes than any non-disabled women or their disabled male counterparts.

Although we lack some of the segregated data, we can take an indication from some of those steps that I have mentioned and from global data. For example, on violence towards disabled women, which globally ranges at the conservative end, from two times more likely to experience violence. At the less conservative end of up to 10 times more likely that disabled women will experience sexual violence.

We can draw some conclusions that gender and disability, when multiplied, will create bias that disabled women face. So, a solution that we need to look at is ensuring that data can be desegregated by gender and by disability. Another solution would be to ensure that we specifically seek the voices and experiences of disabled women through resourcing a women's DPO, if that's what disabled women want. We'll talk more about that later.

We need to ensure that we include a gender lens in women's rights and the disability lens as well. Can I finally say, I spoke earlier this week on a podcast around representation in parliament and Victoria talked about increased representation in the public sector? Can I just say, because time has finished, that some of these AMAZING disabled wahine need to get into parliament and help our non-disabled allies strengthen all our work and outcomes. Thank you.

**JAN:** That was worth sneaking over time for. Thanks. And thank you everyone for your contributions then. So, I am waiting to see if there will be a question that will come through but I just want to acknowledge that the core things that I heard out of the panel. They want to interact with other people's views. Actually, starting from a multi-dimensional world view. And I would say that that is a process of decolonizing our work which is inherent, on our colonial world view, de-siloing and that isn't held in the Maori world view, as an example.

And very strong discussions about the need for quotas. To be able to get that expertise from lived experience as well as analysis within our public sector to also help change, remove the physical barriers within our public service. That also, could be in our parliament, as well.

Plus starting or giving more foundation to this work by ensuring the visibility of experience through the data; recognising that data is the foundation for policy work.

So, I'm not seeing specific questions for the panellists yet so, I wonder if I will just go back to Ronelle to see if you would like to respond, to expand on your own contribution, or respond to somebody else's.

**RONELLE:** Sorry for the delay. I just had to wait for the permission to unmute. I guess, in terms of expanding, I agree with the korero that has been shared. I just recently moved into a new role looking at accessibility for the next census in 2023.

I agree with Paula in that, it's very difficult for us to be making robust decisions to be implemented without robust data to back up our lived experience. In terms of Victoria Manning's korero, fantastic! I'd love to see one of them in parliament. Wouldn't they be fantastic?

It's just, I guess, somebody put it on the chat, very early on, I think before 1:30. Instead of the nothing about us, without us ... actually ... just nothing without us. We really need to be at the table!

**JAN:** Great. Thank you. Victoria ... We've had a question come through which we'd like to respond to and then we will jump straight to the next question. Is that okay with you, Victoria? Then, if you'd like to jump in later if there is any time.

So, the question was, how can we get lived experience as a disabled person, into a person's specifications for a range of jobs in public service? Any of the panellists can respond to the question ... Victoria.

**VICTORIA:** Victoria speaking. I have done some thinking about it and some of you who know me well, know I do not like, or use, the term 'lived experience' because it is almost like past, the use of I have lived experience of being a woman; I have lived experience being disabled.

The term lived is past tense. He lived a good life. I am living. I am very much alive. I carry all my experiences with me all the time. If you are talking about disabled people, say disabled people! If you are talking about whanau, say disabled people and whanau!

But the question was, how do we get it in the person's specification of jobs. Again, we want to stress that we don't want to put a label on us as disabled.

How do we measure disability? It is a difficult one but maybe it is not trying to measure something new. Maybe, it is just recognising we have some skills more than other people. Such as I said, overcoming the barriers, attitudes and discrimination we face every day.

It's almost like we develop these skills a huge amount more than other people do. We just need those skills to be valued. To the same extent that time management is valued, we want resilience and persistence and being adaptable. We want those skills to be recognised along with all the person's specifications.

**JAN:** Thank you, Victoria. I can see in terms of some of the responses, as well as Victoria's, the complexity of this idea and getting this changed. And just to say, I never think it's a bad thing. I think that shows the richness of an idea.

So, the second question is, the government is progressing a new legislative train of work, to improve accessibility over time. They are wanting to introduce this by the end of next year. What do you think are the top priorities to include disabled women and how do you feel this law will support disabled women's needs?

And I'm going to start this time with Martine.

# Q2. ACCESSIBILITY LEGISLATION. WHAT ARE THE TOP PRIORITIES FOR DISABLED WOMEN; WILL THIS LAW SUPPORT DISABLED WOMENS NEEDS?

**MARTINE:** Thank you very much. I think it's a great, very timely question. And two ideas that I've had around that one is, before we get to what the legislation should include, disabled women should be involved when that is discussed.

We do not want to write ten submissions to someone non-disable, who's going to develop legislation. So, my point is, there are some very skilled legislative developers out there. Of course, they should be there because some of us may not know the wordings or jargons to use.

But when we talk about what the legislation should include because I don't think many do, please include disabled women in the co-design. Even before co-design, even when we just start talk about the ideas and concepts and then getting into the very specifics, very technical specifics. Because it's up to the technical specifications what is going to be disabling or not. How wide the door is; or how good lighting is, or etc like that. So, it's not just high level; it's some specifications as well.

If I could add one thing that should be in legislation, it is definitely around actually mentioning disabled women in quotas systems. I hate mentioning and highlighting people, but until natural inclusion, we need to be mentioned and hopefully at some stage, that need to be mentioned will go away. Thank you very much.

JAN: Thank you, Martine. Paula?

**PAULA:** Sorry, I'm just getting funny messages. Thanks, Jan. I think the legislation is a really positive step forward.

One of the things I really like about the narrative around this proposed framework is that it is really couched in the social model of disability. It is looking at what are the barriers that exist and how can we break those down. Actually, that will benefit our wide range of New Zealanders. So, I like that social model concept that's so important to us, that the proposed framework is grounded in.

In of itself, it won't realise equality for disabled women. Unless for example, the development of the legislation demonstrates a really authentic honourable Crown-Maori relationship, the needs of wahine Maori won't fully be realised.

The bill has not yet been drawn up. When it is, I guess we will be able to see the approach that will be taken. Assuming it provides both requirements for accessibility and a rapid system of redress, it will help to create a more accessible society. But it won't change everything on its own.

Because disabled women, as we know, face particular barriers and the legislation is unlikely to include an intersectional approach, it might not fully address those intersectional barriers.

Interestingly, we learnt from the experience in Canada that people there were disappointed that the Federal Legislation, which was recently introduced, didn't take account of those important intersections.

Now, it's quite good when another country goes through these experiences because you actually get to really learn from them. We have an opportunity to address some of those things in the legislation here.

The legislation, as many of you know, will be supported by standards. Not all of them will be immediately enforceable, I'd imagine. Depending, for example, on whether sexual, reproductive or family violence services are resourced to meet the standards, then the standards won't be fully realised. So, it will be very important to resource the legislation appropriately.

We also know that legislation, very rarely, on its own, achieves the full outcomes we are trying to seek. We need to also change behaviours and

attitudes and discriminatory practices. With all of those, hopefully, we'll make a difference. Thank you.

**JAN:** Ka pai. Thank you. Ronelle, now, passed to you.

**RONELLE:** Alright, thank you. Kia ora. So, I guess I would just carry on from what Paula has said and that I believe that it will be a strong lever.

While it doesn't necessarily address specifically the needs for disabled women, it will be a strong lever. It champions better access to goods, services and facilities. I think some of the benefits will be universal, but specifically for women, I think reproductive health and maternity services in particular need to be more accessible. I would like to see this legislation actually supporting more advances in that space.

Women, at this conference today, who are wheelchair users, work with some type of impairment. We'll find that we're not getting many smears, it's really difficult. How hard is it to find a medical centre with high-low bed so you can just get a jolly smear? Let alone an affordable one. So, there are a lot of things that can be enabled, I think, through having this act in place.

In terms of my parenting genes, sort of more what recreational spaces, schools, things, that as a disabled parent, I can access easily with my child, would have been really good. So again, this would be a strong lever for more inclusive spaces. If we think about inter-generational families, we have our older grandparents with us. And we have people who stay with our whanau. I just want to see much more opportunity for advancing inclusive spaces across the board through this act.

**JAN:** Thank you. And now, Victoria.

**VICTORIA:** Kia ora. I'm just wanting to support everything, everyone has said so far. And absolutely, all those points are really important.

If I can just expand on Martine's point, I think the really important thing that we need to try and get right here is to make sure that the voice of disabled women, is in, from the start, the first discussions right through to the end, and the ongoing monitoring. So, we need to make sure that the consultation processes are accessible and include disabled women, that we support disabled women to have a voice there.

When it goes to select committee, is the select committee process accessible? Is their information clear, easily understood? Why? We need to have a voice there. Not only the public consultations and public select committee space but behind the doors in the public service as we've talked about. The importance of

having quotas there, at the table, at the decision-making table, we need to make sure disabled women are there.

In drafting the law, this needs to be co-created with disabled people and disabled women. As Paula has mentioned, it is expected that this law will have standards included in it. Those standards will likely have a huge impact on us. We need to be there co-creating those. And once standards are developed and us co-monitoring them, having a hand in all of these, from start to finish, is critical. We cannot underestimate that. There is a lot of room for improvement there. This is where we can collectively make a difference. If we can get in there. Thank you.

**JAN:** Great. Thank you, Victoria. I'm waiting for specific questions for any panellists. But in the meantime, maybe I'd ask the panellists about any good examples or what you think is needed to be able to have good co-design. Because I hear this phrase get used quite often. It's part of the public service practice but I hear different views on when it's good and when it's not. So maybe, I will just actually go to Martine. Maybe?

**MARTINE:** A good example, for me, is when the first lockdown started, of Covid-19. So, immediately our whole world was changed. If people had just sat back waiting for someone else to do something we would still be waiting. Immediately with the international disability agencies and the organisations lead and they started to survey and research disabled people to see what's going well, what's not going well.

Some of us got surveyed out. I was just sitting sometimes, here in my lockdown thinking, here's another survey! People are now saying to me, this state of lockdown – what are you experiencing? This is the plight of lockdown because we now need to be prepared for emergencies, you know.

Emergency is not just out there in the Pacific or anywhere. It's in our own doorstep. I think that to me was a great example where something is happening that no one could foresee or saw. Then, you immediately start to say to people who might be affected, and as good examples too because let's face it, somethings went very well with Covid.

Lockdown – there is now less angst around working at home, away from an office. You don't have to be changing desks from 8 to 5. People do believe that we can be constructively working away from the office etc. People developed their resilience. Let's look at some of the positives. So, that is my example of capturing the negative and positive at the very immediate and a very high level. And that's what the international disability agencies and some of the affiliate organisations do. So, we have great documents now on what has been experienced by disabled people from day one. Thank you.

**JAN:** Great. Thank you for that. We have some written questions that have come in. So how does the New Zealand parliament deal with disabled issues? And I wonder if Paula would like to have a go in answering that.

**PAULA:** I'm coming. Here I am. Thanks, Jan, That's a really big and really important question. You know, one of the interesting things is our parliament which is a house of representatives has at least, as far as I know, has one disabled member of parliament who openly, publicly, identifies as being disabled.

Of course, it's not to say that there might not be other members of parliament. But, at least, publicly, we understand that there is one. So, I think that representation in parliament is essential, actually really critical around role modelling with the disability community. Around that authenticity, and that experience that we, as disabled people, can bring to the very, very start of that policy development and in having those discussions.

There have been many times where I have observed some key legislation going through and sat in the chambre, sort of the top of the gallery looking down and really hitting home how important it is at the very start of where some of these ideas are debated, for disabled people to be there. And for the public to see disabled people and their very authentic way, see themselves, see ourselves reflected. That's of course, not to diminish the work of any member of parliament, or any political party.

I think outside of that there is all of the process before we can get to parliament. I think Victoria touched earlier on the importance of having disabled people in the public service. It also is about members of parliament and ministers feeling confident that they're getting advice where their officials have co-designed and really collaborated with the community.

So, those are just a few things. I could probably spend all afternoon talking about that. But that's just a couple of thoughts, Jan. Thank you.

**JAN:** Thank you, Paula. We've only got a couple of minutes left before we need to move to the next question. There's another question about the government signing up to the WHO and the technical package? That is not something I know about. I was wondering if there is anybody on the panel who does.

So maybe, we'll have to look into that. That's giving me some homework and I'll go and find out about that. You can email me if you want to find out the answer. So, thank you for putting that question.

So now, we'll move on to the next question which is, why do disabled women need both the Convention on the Rights for People with Disabilities and the Convention for Elimination Discrimination Against Women? I will go to Ronelle.

#### Q3. WHY DO DISABLED WOMEN NEED BOTH CRPD & CEDAW?

**RONELLE:** Thank you team. Okay. Kia ora. So, I guess I just need a disclaimer here. Hu would be all over this question and I would just like to acknowledge that there are people on this panel who will know more about the conventions that I do. So, I guess simplistically, I would say, quite simple, our experiences are different and are, also, you know, if I look back at the history and the timeline, you look at CEDAW, it was adopted in 1979, I was born in 1972, if you put that in context, then Whina Cooper led the Maori Rights March in 1975. So, it's been

around a long time. The Maori Women's Welfare League was founded in 1951. So, shout out to them, you know. They pre-dated any of these conventions.

So, the CRPD was adopted in 2006. So, it's relatively new. So, we can see that CEDAW came first; had quite a long history, a track record before the Rights for Disabled People. It started to be, I guess, really advanced and we started to have our voice more front and centre in policy development in supporting our rights to live, I guess, a life free from discrimination.

So, I guess, there are really crossovers; the principles of respect, equality and the right to live free from discrimination are consistent. Looks like we've come a long way. We still got a long way to go.

JAN: Well done. Thank you. Now to Martine.

**MARTINE:** I think we need them all... there's so many frameworks. If only our highlighted rights are identified in one, namely CRPD, people will just forget us ... and oh, by the way, as an add-on, here is CRPD.

So, we actually link all the frameworks with the sustainable development goals and CEDAW; it could be the universal periodic reviews that countries do, also the socio-economic reviews. So, I think link them all whenever we report back on a specific framework, we link in all the others so that we don't have an alone standing disability tool that we beat people around with. But a really integrated approach. Thank you.

JAN: Thank you, Martine. That was concise and very clear. So, Victoria.

**VICTORIA:** Thanks, Jan. Similar to Martine, I think that there's lots of tools out there and we need to use them all. So, the convention on the rights of disabled people puts that disability lens on top and says what is the disability experiences and how do we reduce barriers and quickly create equality for disabled people. That is a very important tool for us.

Then we've got the Convention on the Elimination of Discrimination Against Women and that puts discrimination against women as the primary lens. We are disabled and women. We are overlapping in that and the word intersectionality has been used a lot in this forum, in this conference. I think that's very relevant here because there are so many intersectionality's. Being a disabled woman is just the beginning of who we are as people. We have many. There are other tools and we should be using all of them, every tool.

There is also another significant one for us, the United Nations Declaration on the Rights of Indigenous People. That's another very important one for us to consider here and we need to as I said, using all the tools. Also, using this multi-pronged approach, it gives us an opportunity to collaborate with other groups and other people and to learn from each other. To teach other groups and so we can teach other women's groups how to be accessible for disabled people and vice versa. There's huge teaching and learning opportunities and sharing our experiences because what we find is that as marginalized minority groups, our experiences are very similar. We can gain a lot of strength by pooling those resources and working together, so that we're all creating a more equitable world, not just for disabled women but for everyone.

**JAN:** Beautiful. Thank you ... and Paula.

**PAULA:** Thanks, Jan. So, like others, I absolutely think that it's really critical that we have both. As Victoria really nicely put, there are other conventions and declarations that are also critically important to us. CEDAW, as we know, focuses primarily on equality between men and women, but it doesn't clearly articulate women's diversity or measures that we need to take, to dismantle those inequities. As many of you will know, without the strong advocacy of disabled women to have the unique experiences of ourselves specifically included in the CRPD, the disability convention would not have articulated the rights and unique experiences for disabled women. I think that's really important.

We have been really slow I think, not just in New Zealand, but globally to take a truly intersectional approach. One of the things that I find really sad actually, in my role, is when people talk to me about having to pick one identity over the other, because when one of their identities is as a disabled person, they often find that that's the one that they have to forego in order to participate in other groups that they identify with. I think that, you know, getting intersectionality right, is really important. And until we do, then I think we need these multi tools and a number of conventions. I think we can use both the CRPD and CEDAW in support of each other.

So CEDAW has as Ronelle mentioned, a much longer history. So, we can draw from some of the thinking and the jurisprudence arising from that. You know, we can take that analysis and apply it to the disability convention work. We

often talk about leaving no one behind and I think we really do need both of these treaties if we aren't to leave disabled woman, in all of our diversity behind.

**JAN:** Kia ora. Thank you. And just to respond in terms of some of the points that I heard in that round, it strikes me as if the goal is for everybody to be free and respected. Then it is dealing with the whole, in recognizing the strength in all of our differences and which is that point about not fitting in pigeon-holes and being able to use an identity as a source of power, but not being restricted by it. And I really, I want to love that point around the opportunity to learn and teach across groups. In terms of just waiting for another question, just to acknowledge that there was a response about the WHO-inspired technical package,

if for those others like me, who may not have known what that was. Apparently, it draws policies together and utilizes the good from all, plus using the data that we've collected and that we're lacking, that glue to bring people together. So that sounds like a really interesting tool to explore. And it's not a technology so it's okay.

I'll leave that there. So, I'm waiting ... Also, if you want, we also can take some remarks from our amazing panel. You all are amazing women, with powerful stories, really representing very well.

**RONELLE:** You know, I've been thinking about this. You know, we need representation as a group of disabled women, we should be working together to get someone there and I think with oppression, it will never be the oppressors saying, oh, okay, all right, we're gonna stop enslaving you guys, you know. As for the women when they started to vote. Did the boys say, okay, women, you know, can vote? No! The minorities, they organize themselves. They fight and as Victoria put very, very well if you have a disability, I bet you are really resilient because it's an everyday exercise. And I think I can talk about it because until I was 19 years old, I had no disability. Then at 19 I had a malformation of the spinal cord and became a person with disability.

So, I know please, how clear the difference between being, you know, those two, different intersectionality's and you are the same person. I'm the same person. Why? From day one that I sat in the wheelchair, I lost so many rights that I took for granted. So, I have it crystal clear in my head that we need to organize ourselves and we need to choose.

Okay, so who do we want in the parliament in the next election? We want Victoria. We want Paula. Who do we want? And we need to claim it. You know, or it won't happen and they say ... oh guys come here help us to design the disability legislation! No. We need to say enough is enough and do something, like the crip camp.

I don't know just thinking aloud. Girls let's organize something and I'll do like a protest and go to the beehive. And yeah, this thing is happening.

MARTINE: And I think there's also there in looking at smaller levels of government to getting grassroots representation and local government and some of the very local initiatives that look at the differences in our different communities and we figure out the CEDAW and the CRPD. You cannot talk about discrimination when you talk about disability yet lack of accessibility is discrimination. You know because there is a job offer, there's a job offer there and everybody can apply. Oh, but there are the stairs to access that building to work, for that job. So, you're pretty much discriminating against all the people that cannot use the stairs to apply for that job. That is discrimination, right?

**JAN:** Just as I was going to go back to the point around the taking over of Parliament in a good sense, and getting representation in parliament that historically, and I guess this is the problem with not having good intersectional work having happened earlier, that there was a women's electoral lobby in Aotearoa where women came together and supported each other to learn about the political system and to, in effect, train to be able to get themselves to in a place to run for parliament. It provided organizational support for those women, sometimes in really practical terms, in terms of childcare and provision of money and buying of fancy clothes. I think, there absolutely could be value for people considering that from disabled women's group.

**JAN:** Okay great. And this is the last question for the panel and I too, just want to take a second to again in advance of the last question, to really acknowledge the expertise of these are women, who have been dealing with the system and thinking about how we break through to create that inclusive society for a long time. It does feel as if we're in a moment of time where it's great to pull these minds together to see if we can speed up this process of change.

So, the last question is, recently the UN CEDAW Committee asked New Zealand government to do an interim report on four points, including implementing the Family Violence Act and to do something about the abuse between disabled women and carers.

I spoke a bit about this and I'd be really interested to hear from the panellists, your ideas about where we're at and what we need to do to progress this work. And I will start with ... I'll go back to the original programme, with Ronelle.

Q4. The United Nations CEDAW interim report included Point (26a) This asks the NZ government to implement the 2018 Family/Whanau Violence Act and do something about the

## abuse between disabled women and "carers". What do you think should be done?

**RONELLE:** Alright. Kia ora, Jan. So, this is obviously a difficult topic. And because I have a progressive condition and multigenerational experience of that, now I'm going to reflect a little bit on my mother's experience in this korero.

It's obvious as we transition over time, that the loss of functional independence means we rely more and more on personal care to live the lives that we want to and choose to.

And I guess I'd like to speak a little bit about the subtlety of abuse. I think under the family violence umbrella, it's really important to think about the subtlety of abuse that happens in the care relationship. It's such an intimate relationship. Minister Sepuloni mentioned a few things around withholding care, withholding equipment, resources, and food. You know, things that people don't often associate or recognize as family violence.

And I think in my experience that persons with a disability tolerate a lot. They actually have a high threshold. Things often get really bad before someone has the courage to speak up. So, in terms of solutions, well, I think we need to have more of an honest conversation amongst ourselves about both the subtle abuse that happens by both paid and unpaid carers. Our paid carer workforce is largely women. So, we need to have an honest conversation about women being perpetrators of abuse in the care workforce. I think that you know, that needs to be talked about more openly.

I think disabled women need more peer support and encouragement; for safe forums to speak up and describe how that is for them and how they can be empowered to take more control over their personal circumstances.

Thank you. I think certainly individualized funding, choice and control over support has given people a lot of enablement and empowerment and this is where I would just reflect on my mom's experience when she was living at home alone as a full time powerchair user. She experienced abuse in a care relationship when she moved into rest-home level care at the age of 71 because she had bilateral hip fractures. She experienced rough handling and very subtle abusive care from paid staff.

So, you know, the critical thing in there as leadership, organizational culture, institutionalisation but ultimately, she didn't have choice and control over who was supporting her in a very vulnerable state. And if I go back to something Victoria said earlier about people leading and managing. Yeah, actually this is part of our call to leadership. We should be doing more than monitoring, not only in the public sector but in the private sector and the care sector, we can be

leading and managing these services. Changing the culture from the top down, inside out.

JAN: Kia ora. Thank you for that very thoughtful response. Next, I'll go to Victoria.

**VICTORIA:** Thank you, Jan. I have a policy background and being a bit of a policy geek, I did a little bit of research on this question and there are some quite practical and easy things to that the government could do here to make a significant difference. Part of this work programme includes the development of a National Strategy for the Prevention of Family and Sexual Violence. That national strategy needs to be co-created with disabled women there creating it.

We have heard from Ronelle in just two minutes, a wealth of knowledge there. People like Ronelle need to be co-creating this strategy. Another thing in this piece of work is increasing the funding to family and sexual violence services and we know as disabled woman those services are a significant barrier to us. Often, it's insignificant things that can make a big difference. that can disable us in many ways. So, we need, again, we need disabled women there giving advice on how to make sure that all of those services are accessible to all disabled women.

Also considering the conversations around potentially developing more specialized services that are just for disabled women that are built from the bottom up with a disability cultural focus. There is absolutely merit in having those conversations and those services as well. Then disabled people, or disabled women, have the choice to go to a mainstream service or specialized service.

Another thing in this piece of work is data and we've heard already that data is so critically important, and Paula has talked in detail about that. Again, it's making sure that disabled women are in there in terms of creating that data. What are the data questions they're going to ask? And data analysis, I'm so thrilled that Ronelle's got this new job at Stats New Zealand. It's going to lead the way there and the questions need to not only ask about what your disability is, so we can track that but also, support needs, because as we know, some women do not want to label themselves as disabled, even though we might think they have a disability. And that's absolutely fine. If we focus on what are your support needs and then make sure they are in place, then that's important data to collect as well.

The last thing is, it's a little bit of a sidestep here, but we do know there's a lot going on in the disability system. A lot of potential changes happening with the enabling good lives system transformation. You know, the health and disability review that recently came out. There's a lot going on in that space too, that can impact on the services that disabled women access and again disabled women

need to be there co-creating and all the monitoring, co-monitoring from the start and through it all. Thank you.

**JAN:** brilliant. Thank you very much. A lot more detail and depth to that, adding on what was already really impressively presented from Ronelle. So next to Martine.

**MARTINE:** A couple of things from me, apart from what the others already raised, I think we've just, earlier this year, have completed some research and in my role on the ACC Sexual Violence Prevention Board. For the first time, we contracted an agency and they did some research into sexual violence prevention. It's just at a New Zealand level, because we keep on seeing the stats, there's a lot of international research. We've now published that report. It's not perfect, but, you know, you have to look at the scope. I think the more research we do, the more we can strengthen our evidence and our creditable data.

So, I just want to assure people that as we speak, some of us are really pushing for more visibility and promotion out there.

So, yes, continuing from that ... secondly, then I want to say thanks generally for promoting it, and Paula Tesoriero, for minimal payment for some of us working with the JBBU. In the first week of lockdown, of the pandemic, a sexual violence prevention group got started that met every week. I was asked by the DPO coalition to be on it and I'm still on it and as of March, it is still free. Then, I was told by Ministry of Justice and the MSD that they'll pay for their officials but not for disabled people being put forward.

I do it because my passion is in it. I wanted, a friend of mine, who is experiencing abuse, to do it and I knew that she wouldn't have the time and the energy because of the abuse she went through during covid. Her carer basically said to her during shopping,....the longer we spend time together, the more we can get exposed to Covid. I don't know why you want to buy cosmetics over this time. She wanted a specific brand of sanitary products and the patience wasn't there for her to find it?

That sounds very subtle, but that is really an abusive situation in that key situation. I wanted her to do this work that I'm doing now or help out but I would feel so bad to ask you to do it for free. So, my example is, yes, it's happening all the time and please when you do contract people, especially if it's experienced people in abuse, respect and value them.

We had some awesome deep sharing today, which I'm very thankful of, which I can't say how much I appreciate. Then I want to say please contribute to those people's quality of life. And just on the last point, every time, do note that every time you are sharing your experiences, do share it. It finds a place in my

heart, and I won't just abuse that information. It will spur me on to do more in this area. So, thank you very much.

**JAN:** Beautifully put, Martine. And I would say that goes for me as well. And lastly, to Paula.

**PAULA:** Kia ora. Thanks Jan. I can see that the Honourable Marama Davidson has just joined us. So, if she's there, but we can't see her, welcome Minister.

I just can't do justice to this topic in the short space of time, so I'll make some rather quick observation. Firstly, Jan thank you for all the mahi that you did around the family violence legislation. There are some really good things in there and I think particularly around recognizing the nature of the relationships that ought to fit within the legislation and now we know the carers are part of that and I think, you know that has certainly opened better opportunities for protection within the disability community.

One of the things I often talk about is that in this area, the magnitude, the nature and the prevention of violence is similar but different in the disability community. There are some things that are the same for everybody who experiences violence and abuse.

We know, we know deeply that there are nuanced differences for the disability community. And if we take a universal approach to this work, we simply will not, as a nation ensure that disabled people are not left behind. So, what do I think needs to happen?

I've been really clear in what I think needs to happen and that's been informed by so many wonderful disabled wahine around the country, academics, people who are skilled in this area, who have helped guide my journey around this and my understanding around this. I want to thank those disabled women, some who are part of this conference and continuing to help me with this work.

Firstly, Victoria touched on it. Absolutely, there must be the full engagement of disabled people. And let's not forget our disabled men also, because we know that they experienced greater levels of violence than non-disabled men. I'm really pleased that we have now a group of some amazing disabled people around the country who we've been able to facilitate greater work with the joint venture of family and sexual violence.

I think there needs to be comprehensive disability sensitive training for everyone. Police, family violence, health and disability services around rights and responsibilities connected to the current system so that their practices are inclusive and they understand the unique risks and the ways in which abuse manifests itself.

We must, and I've talked about this, we absolutely have to improve our data and evidence. We most certainly, I believe need specialist services and our mainstream services. I'll touch very briefly on the need, the critical need for our mainstream services to be resourced, to be accessible. During lockdown, I made contact with all the main service providers.

I asked them what, during Covid, would they do to particularly reach out to disabled people? The response I got from one of the main service providers was Paula. I cannot and I will not pretend that our services have ever or will ever cater to the needs of disabled woman.

That is utterly unacceptable for New Zealand. I don't blame that service provider. I think all our service providers need to feel they are resourced and they have the level of understanding and the workforce development and knowledge in this area.

Finally, not finally, second to being final, we absolutely need to have a comprehensive integrated safeguarding framework.

Finally, I think attitudes towards disability, towards disabled people is something that we also need to have a national conversation about because across every domain, violence and abuse being one of them, if we can start to change attitudes, I think we can also make a difference. So, thank you. Thank you, Jan. Thank you to wonderful colleagues and the disability community who just continue to challenge and inspire me to do a great, great job, the best job that I can. So, thank you.

**JAN:** Thank you. And I will thank you again for your intervention, which went beyond just the report actually. It is all the work around the consultation and bringing community together and raising that to a political level, as well as the very regular and continued conversations with our public service. I really think without it, I don't think I would have the same confidence that we will be able to achieve the change that we need to. And it is about all of us being able to come together to be part of these solutions, so thanks so much. That was just like there was so much detailed information in those four answers coming from a range of perspectives that I hope everyone really, really values as much as I do.

I just want to pick up. There was a question that came through from the list, for the panellists of what do you think about coercion? Why do you think coercion and control was added to the Family Violence Act? And how do you think it will help disabled women and the support staff in their home? I'll leave that to anybody who would like to jump up to answer that.

**PAULA:** I'm happy to make a comment, Jan. I'm just trying to get my video on. So, thank you for that question whoever it was that that asked that. I think that, that change was one of the real positives in the legislation. It does

recognize coercive or controlling actions such as and I think this is really important for our community, it includes things like removals or threats to remove support or assistive equipment and things like that.

So, I think that is quite important. I would go on to say that I think the thing which would really compliment achieving the vision of that legislation would be that point that I made around ensuring that there is that disability sensitive training so that when police and other frontline service workers are going into those situations where they have to make that determination about coercion and control, they have that disability understanding and awareness to be able to respond appropriately. I think that that will be an ongoing challenge for all service providers to respond to. So hopefully that helps a little bit.

**JAN:** Great, thank you for that. And I would add that I'm hoping one day to see that translated, that sensitivity training to the police when they go to callouts around family violence. That they in effect have a checklist of things that are looking for and questions that they ask, is what I'd love to see from that training. The actual needs and the potential risks for disabled people in that list, in terms of when they're called out.

I just also want to point to a comment from on the chat, somebody saying ... asking if we can stop calling people "carers" and saying that's not really the case. The role is personal assistant or support staff. Even for family paid in that role, it becomes a role of paid assistant amongst other roles of parents, friend, etcetera.

I think in the materials for this conference, "carer" was in italics. That is the language in the legislation because that was, I think the legal term at the time, and that was the kind of the fight that had been developed for that. But I do want to recognize that point, particularly, when people are experiencing abuse, that is clearly not care. So, thanks for raising that.

I just wonder now before we wind up whether, any other panellists would like to make a very last short last intervention, maybe once one or two sentences to sum up your key takeaway you would like people to leave with from this whole discussion, starting with Ronelle.

**RONELLE:** Kia ora, Jan. Well, I guess, you know, first of all, thank you. It's been a wonderful privilege to be part of such an exceptional panel. I really enjoyed listening to the korero today and also the chat. Thank you to everyone for your engagement there, it's been really insightful, and I'm looking forward to going through that in more detail when I can focus on the conversation.

Look, this has been a fantastic conversation today. I think that that will be ongoing, you know, ongoing spinoffs from today. It's a bit of a movement I can see coming and what strikes me is how we are so highly relational and collective in the way that we think that you know, I just find that really

empowering base to be moving forward from. It feels like a really mana enhancing opportunity and so yeah, fantastic.

I really like the opportunity to think strategically and for this using the framework as tools, as Victoria has mentioned, and looking at how we can bring them together so kia ora everybody. Thank you.

**JAN:** Kia ora, thank you ... Victoria.

**VICTORIA:** Okay, I have been in the disability sector for forever, but I still really love places like this, these spaces where we come together and we share our collective knowledge and wisdom and it's so, it just gives me so much energy so let's get together and keep shaking the boat and making a difference. And yeah, it's a goose bump moment to be here.

In the earlier panel there were times I had tears in my eyes, You know, this is very, it's an emotional journey for all of us and just to come together like this, that we can't undervalue that there is huge value in doing this. So, I'm looking forward to another one of these sometime soon. Thank you to everyone for participating. One last comment. I do like to reframe.

Sometimes people's assumptions about things and I think that we, as a collective, we all understand that future that we're going to, where our world is equitable for all of us. We understand that we have a very clear vision. There are a lot of people in society who don't understand that vision, we must drag them into the future with us. So, let's collectively do that.

**JAN:** Kia ora, thank you. And Martine and then Paula and I've been asked by the organizers to ask you to keep it short. Sorry, otherwise it'll be too far over time, but I'm just loving what you're saying, so much

**MARTINE.** Martine: Hi, everybody. Thank you for the shared space. I think it's a great example to capitalize on and do again and please let's use this energy to move forward and not just to stay in place.

JAN: Thank you, Paula.

**PAULA:** Nga mihi nui everybody. Jan, thank you for emceeing. Thank you to my wonderful co-panellists for all your contributions. Obviously, sorry that Huhana couldn't make it today. She would have added some more lively points as well. I started my day this morning, actually presenting at another conference. It's a global conference called Her Story. And its women from around the globe telling their stories. I started that quite early this morning and then I listened to some of the stories. Some of which were grounded actually, in violence and abuse. I think it got me really motivated, even more for this part of the day.

So, to finish with wonderful New Zealand women and having this conversation has been really beneficial. Thank you to everyone for all your work. Jan, thank you for being a great ally. And you know, I'll start, I'll finish with the cheeky suggestion that I started with, which is, let's really make sure that in three years' time, we've supported some wonderful disabled wahine and our disabled men, to get into parliament and help make a difference there. So, nga mihi nui kia koutou katoa.

**JAN:** And just as a very last word, I just want too really thank everyone again for your wisdom, your experience, your expertise, and the path forward that you're offering us. This government is working towards an Aotearoa where family violence and sexual violence are an aberration and not the norm that they are now. And that is not possible without your expertise and tailoring responses that recognize the dynamics of violence experienced by disabled people. So, thank you so much. I am really looking forward to hearing from my amazing, wonderful colleague, the honourable Marama Davidson next.

#### Conference on Disability: Creating a level playing field for ALL women.

Speech by Minister for Protection from Family, Sexual & Other Violence, Marama Davidson,

**Marama:** Kia ora. Tena koe, Jane. Tena koutou zzzz . Tena koutou everybody that has been able to join what I can see, what I can pick up, has been an incredibly inspiring discussion.

I'm so proud to be able to be a part of coming in to help to close this particular part of the discussion. Jane, it's good to see you even if it's on zoom. I recall the many, many incredible occasions and times that I have been able to work with zzzz New Zealand over the years, especially during my time at the Human Rights Commission and leaning into the broad platform of uplifting the rights of women and girls.

And I also want to acknowledge my Iwi and Hapu, from Te Tai Tokerau, Ngapuhi and Te Araroa and also from Te Tairawhiti, o Ngati Porou, Te Naimoko Whanau.

I'm here in my Auckland Green Party office. We have just finished an all-day workshop with our Maori members and so I apologize that I was unable to enjoy more of the incredible discussions today. We managed to finish a little bit early and I managed to jump on, I think, the bulk of the family violence and sexual violence question at the end of the previous panel. So, I'm hopefully going to have some time to quickly referred to some of the points that were raised as I, was able to steal some time and jump onto that.

We all want Aotearoa, our beautiful, beautiful country, our beautiful whenua, to be a safe place for everyone, for all our children, for our families, for our people and for our communities. We have an incredible opportunity to work together towards that because unfortunately, we all know that family violence and sexual violence is far too common.

As my incredible colleague, Jan Logie referred to, we want to work towards family violence, sexual violence, all forms of violence, not being the norm. And so, I am incredibly deeply honoured to pick up the role of Minister and improved status of the role, which is important. It is where I acknowledge the incredible work that as Undersecretary, Jan, was able to set and push them through some incredible challenges in trying to transform the whole system; the way that we are currently used to working in isolated and segregated ways when trying to address and reduce and end the high rates of violence. I am now able to pick that work up as a Minister.

And I know that that means a lot to government departments and agencies. That increased status is something that I am ready to lean into and ready now to lead the work across all our systems, government, community and all of our other sectors. That is because, and I feel like I need to state the obvious to be really clear about where I stand as a Maori woman, as a mother and a grandmother on this issue.

The family violence and sexual violence creates intergenerational trauma and in particular, impacts on children and adults, on health, on well-being, on generations, and in our whole communities generally. So, I want to acknowledge that in that harm this is particularly the case for disabled people and for communities, and that disabled people experience twice the rate of violence faced by non-disabled people.

The rate of violence faced by disabled children is three times higher and that disabled women and girls are more than 4 to 10 times more likely to experience sexual violence and that those numbers are absolutely outrageous. They're not just numbers. Those stories that harm which is happening to real live people and people we know and love, should not be tolerated.

So, there is an increase in my determination to make a difference as I begin this role because of that reality. Just speaking quickly to my own personal background, at this, you know, family and sexual violence, Family violence and sexual violence is personal for me, as it is for far too many New Zealanders, whether you have used harm or have been harmed or both, or someone you know, and or love.

I was the chief panellist on a nationwide inquiry into domestic violence and child abuse some years ago. It was clear to me how broad and deep the harm is, even when just one person is heard, it's never just hurt to one person. It's a shattering of entire peoples' lives and whole communities and families. And I carry that with me to help drive this work every single day that I wake up with the privilege of this role.

As I expect, you'll be aware, one of the key focuses of and priorities of the Joint Venture, the Joint Venture established to drive transformation of whole of systems approach. Over the coming year will be how to better meet the needs, particularly of a range of communities who are both impacted more and harmed more. Therefore, there is a neglect from prevention right through to response for how to be able to support those particular groups. And this includes disabled communities as well as rainbow, older people, older person communities and new migrant communities and recognizing that many people fit into not just one of those communities. I , as did Paula acknowledge, for example, our incredible leader, Dr Huhana Hickey.

So as you know, I'm new to being a Minister and one of the first things I wanted to point out was I am primarily here to listen and learn and I want to be the best ally I possibly can, that all that I carry with me all the time, that I am constantly learning across a range of issues, but especially when it comes to, how can I be the best support to disabled people? How can I be the best learner?

It comes down to the language that I use, the framing that I use and the thinking that I draw from. I'm aware that that will continue while I continue to also be a leader in this work. Some of the key points that I was able to jot some notes down as I was listening to the last section of the panel, absolutely, hear that bottom-up services specifically for disabled women, to be able to give disabled women that choice of choosing from a range of services, as is appropriate.

That we also need to include disabled men in our engagement in our thinking because disabled men are impacted and harmed more than non-disabled men. That the data, both the questions and the analysis have. That process has to be led with and by disabled people. It's so important that we get that basic stuff right, that all of this is actually about affirming and affording power, equity.

I did want to acknowledge that in some of the comments when it comes to government very much uses the words the terms, for example, co-creating or co-design.

I also sometimes hear from Maori communities as well, where we need to watch what we mean by that. It cannot just be simply a token approach to getting people's thoughts and then not going forward and not honouring decisions that are made by the community, who need to lead that design.

I do lean on communities leading discussion, engagement, design and decisions. I wanted to particularly, there was a lot in there, but I wanted to pick up on the examples of coercion and control and one of the examples that I hear is things like threats to pets when we know that is already an example of removing support or something that may seem non-threatening, but in actual fact is and I acknowledge how important that part of violence is in this discussion,

I did want to pick up that whether it was in the comments or what I heard, I've written down the power of storytelling and as a non-disabled person, I wanted to pick up that most often, that is what connects my heart and mind into having an authentic understanding of someone's reality that is different from mine.

And I did want to appreciate the power of storytelling led by disabled people and how important that is. Absolutely heard getting more incredible disabled women into parliament. It's not acceptable to me at all, that we do not have

either any or enough, at most stages of parliaments and successive parliaments over the years.

I wanted to raise one particular example. I saw some mention about Oranga Tamariki, and I wanted to acknowledge that many disabled women have come to me personally actually, long before I became the Minister in this portfolio to highlight the absolute injustice of disabled mothers in particular being threatened and having children removed from them purely because of being disabled.

I wanted to acknowledge that injustice and how for me and my role, that will be a real key part of transforming the way that government works. And I guess that I might sort of round up with what I heard is that I acknowledge that creating a safer Aotearoa depends also on some very basic provisions that you would think are basic but have never been properly afforded and accessible in Aotearoa, including something as simple as having an accessible, affordable, healthy, stable and long-term home and having adequate incomes to provide for ourselves and our families. That those seemingly simple provisions which help towards having a safer communities and safer homes have simply not been afforded, have simply been denied for far too long.

So, in closing, I want to acknowledge that yesterday I was privileged to attend the White Ribbon breakfast in Wellington. Yesterday morning and I had a wonderful opportunity to quickly but importantly, catch up with Commissioner Paula Tesoriero. And again, affirming how important that I am keeping and learning the work and the priorities from disabled people from disability communities at the forefront of my work and I'm very grateful Paula, that you're making family violence and sexual violence such a strong focus of your work for us this term and that I know we have your generosity to expect that engagement and that ongoing guidance and leadership for us and for me and my work as well.

At the same time it will be important for me to hear directly from community and directly from people and disabled people. This is one of those opportunities where I want to genuinely invite people to reach me directly in whatever way that is appropriate for you. I want to hear directly about what you're seeing working well and not working well. If that is something that you would like to do alongside all the research and the partnership that we will be working with various, different agencies to get that information as well. I just want to get it right here. I wanted to just make sure I left with at least my email <a href="Marama.Davidson@parliament.govt.nz">Marama.Davidson@parliament.govt.nz</a>. If I can find my chat, someone might want to add that into the chat as well. I want to finish simply by thanking you all for your mahi and where I've gone over time, I apologize. It was just really important. That I wanted to come and acknowledge the mahi and years and generations of work to improve support for all our communities, for mahi over the years. I want to again acknowledge the mantle that I am picking up from my incredible, amazing friend Jan Logie who has laid the foundations that I'm

going to build off. I'm absolutely committed to this mahi ahead and the challenges and the celebrations and I look forward to working more closely with you. Kia ora koutou katoa you. Kia ora koutou katoa.

# Conference on Disability: Creating a level playing field for ALL women. (PART 3)

DWF: Informal meeting/discussion for disabled women only.

## DWF private discussion

Opening Remarks: Human Rights Commissioner for Disabled People, Paula Tesoriero.

I know it's been a really big day. A lot of us participating in today's really excellent of it. Thank you, Lorri and others from Pacific Woman's Watch. You know and I know, it would be really hard to get all our diaries aligned and really organized.

I think one of the things that we emphasised on the panel discussion that I was part of this afternoon, was that in our disability rights we need to include a gender lens and our women's rights, we need to include also a disability lens and that came through in their conversation around the importance of using both CEDAW and the CRPD.

We also talked a lot about intersectionality and the importance of that. I think it's great to have these spaces. We don't have many spaces like this to share and strategize and think about how we want to be in the future. So, I think this is a really great way. Actually, to finish the day, that we need these spaces to share our experiences and insights, our knowledge and ideas.

I know we will be doing that today We need to be able to hear our concerns and to commit as a collective and individually where we can. To continue to raise these issues. I see so many brains look back on the screen. I know you are all involved in a lot of advocacy and I've shared some of it with you and you know who you were. Thank you.

I think one of the things to remember as well, is we theorise differences often and whose voices get heard, who might be the privileged voices and who are not, who's on the road, who isn't. How do we ensure that the voices of disabled children, our whanau and families, could we bring to the table with us? And who are the disabled women and children that we might leave behind? So, I think it's important as we move forward to think about those voices.

I think we have this incredible identity as disabled people in common. We also have differences and sexualities that we talked about, and I think they need highlighting. We can support each other, be each other's allies. So as many of you will know this coming Thursday, December third is International Day for People with Disabilities, as it's called internationally and the U.N theme this year is building back better towards a disability inclusive and accessible society,

in a sustainable post Covid 19 world.

We know that woman have been particularly impacted by Covid 19, in terms of employment; safety; home and families, and to say well, likely among the worst impacted. We absolutely must be at the table and ensure that New Zealand includes inclusivity in our own Covid recovery so that we really do have a chance to build back better. I'm looking forward to the rest of this discussion.

## Disabled Women's informal, private DWF discussion followed.

...I think, one of the big challenges in creating a level playing field is actually knowing how uneven the field is to begin with and how big the bumps are along the way" ... Paula Tesorario (DHRC 2020)

#### **Conclusion:**

The ZZZZ -DWF Conference on Disability: Creating a level playing field for ALL women, gave voice to some of the realities of disabled women's lives. Thank you, zzzz and ZZZZ for the opportunity, thank you to all the non-disabled women in the audience, the community and in government, who attended as staunch allies and most of all, thank you to all the amazing disabled women of Aotearoa and beyond; past, present and future, whose strength, determination and belief in human rights equity and equality for ALL, has bought us to this point in herstory and the conference.

There are to many highlights to be re-iterated here, so we will list some of the things that stand out for us in this conference.

- The support of our politicians, doing the mahi together with disabled women ... not just for us.
- Intersectionality has been a highlight. Understanding that regardless of our primary identity, Maori, Pasifika, women, disabled, etc., that we have many other identities and that can result in multiple discriminations we live within on a day-to-day basis.
- Intersectionality also clearly helps us understand that we also discriminate against others on a day-to-day basis. What does this look like? As we heard today, there is no one size fits all answer. If we want to know, we need more forums like this, where we learn to listen to the voices of marginalised women.
- Allies! The importance of allies, we need each other as women living within patriarchy. The future conversations on that topic alone is something we look forward to.

Right now, we are living in exciting times. Nationally and internationally, diversity, inclusion and accessibility are hot topics in the women's movement and CEDAW, as many of our organisations restructure and redefine themselves. Covid 19 has created a time and space to slow people down, to think and talk about the ways we treat each other and what needs to change. We, DWF and ZZZZ , hope the Conference on Disability 2020 has been a positive start for creating these shared spaces, for these conversations on disability in Aotearoa.

In practical terms, contributing to the steps forward and creating a level playing field what does this mean? Paula said the first step is knowing, ... "one of the big challenges in creating a level playing field is actually knowing how uneven the field is to begin with and how big the bumps are along the way."...

This resonates deeply as we make visible the elephant in the room, the cause of many of the bumps in the uneven playing field. Everywhere we go, you know, the elephant that takes up so much space when disabled women are present. If you are also Maori, Trans, Pasifika, Intersex etc then you have to deal with the bumps on the bumps, as we heard today in the Speak-Out Panel.

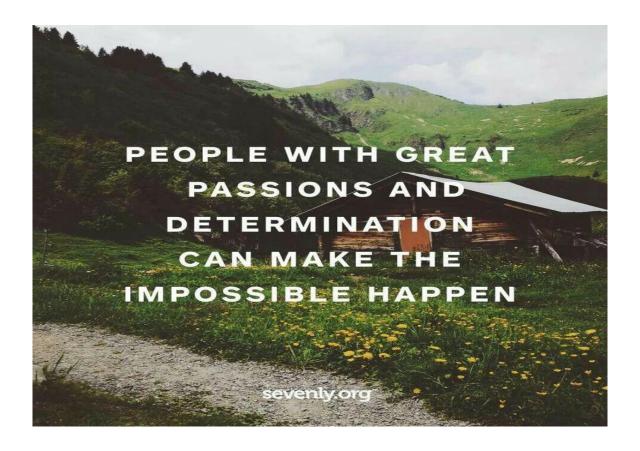
What do we do? We play "nice" and pretend they are not there. What we heard to day is the world is changing, Aotearoa is changing and if disabled women are not going to be left behind, ... and I heard clearly today we and our allies have no intention of letting that happen, then that elephant around our necks, Ableism and all the bumps on top of it, must be named, dissected, discussed and discarded

Today's discussions have been woven with rich threads of experiences and the wisdom gained over generations, weaving the webs that connect us, past, present and future. It is time to remove the fears and illusions of difference that is woven around, under, over and through every part, every thread of the web. To remove Ableism, we must understand how Colonization works, the structures and implementations of Divide, Conquer & Rule, Tokenism, Denial and Deflection, to name a few.

To start that discussion the disabled women who organised this conference will discuss in the evaluation, different examples of the Ableism that was woven into the fabric of the conference, pre, during and post conference. This is done with love and as a gift, so we can learn from each other, heal the hurts and stop discriminating against each other. We look forward to more forums like this and listening and learning from other marginalised groups and the chance to change our attitudes and actions that cause us to unawarely discriminate against you.

As clearly stated in Paula's opening remarks for Part 3 of the conference and said by many panellists and disabled women through out the conference, the importance of having these spaces, to have these conversations from the voices of disabled women themselves, is so incredibly valuable to us, not least because it reconnects and empowers us, as we share our commonalities and explore our differences. It is the beginning of what we hope will be regular conversations between disabled women, shared with non-disabled allies.

Disabled women look forward to going forward with ALL women on the level playing field we are co-creating. It is exciting to think of what we can do together .... the sky is just the beginning .... No Limmits! No Women Left Behind! No women going forward till there is equity; a level playing field between women, then united we change the world!



#### **Evaluation**

1. We have collected and demonstrated many technical techniques, including more inclusive communication, for disabled women across sectors of our community.

We created and provided:

- On-line zoom conference, providing National and International accessibility.
- Conference programme as traditional accessible .pdf for inclusion into invitation EMAILs.
- Conference programme as neurodiverse .pdf, with yellow/green colour scheme and other details.
- Conference programme with reduced graphics for low vision people with screen-readers.
- interpreters for NZSL to include deaf women

We used ZOOM real time subtitles, for deaf people and people who are hard of hearing. These subtitles lagged the actual speech, by a variable amount, which caused moderate problems for many deaf people. The formatting of the text on the screen was rolling text, rather than the normal film style with just the current line of text. This resulted in smaller text, which caused problems for people with poor vision and/or reading cognitive skills. The technical area of automatically generated subtitles is changing very fast and it is expected that these problems will disappear in the next year. However, these issues will need to be checked carefully, for all future conferences.

The Conference organisers had a significant degree of difficulty to apply these techniques and technology. Insufficient time and resources available to test and check these new techniques securely. Nonetheless, on the day of the Conference, it all came together; pretty much the way that the organisers hoped.

It was not just the issues of the new ZOOM software, but how to work these in with the disability needs of all the different groups of presenters, supporting staff (such as NZ Sign Language Interpreters) and all the different participants.

For example, the NZ Sign Language Interpreters could only work for 10 minutes and needed to changeover. As they were at different computers, this required careful management by the Conference ZOOM operator. Changeover times between participants were different between NZSL to abled and vice versa and NZSL to NZSL and disabled to disabled. This was quite complex for the ZOOM operator to stay on top of, right through the Conference.

Somehow, an unknown group of people injected a pornographic video into the Conference. The organisers quickly did a Google search and were then able to remove this video within a couple of minutes. Only some viewers saw the video, I think the participants, through YouTube were spared that intrusion? Even so,

there was quite a lot of disquiet. That is unlikely to be a problem in the future, as ZOOM have improved security management on this issue.

- 2. Although the DWF Conference flowed through very smoothly, with good time management, there was limited affective communication uptake for some non-disabled people.
- 3. The Conference organisers believe this medium achieved substantial affective communication and highlighted disabled women's issues. The video and transcript of the Conference are available for future use. We can work to make the best use of this resource in the future.
- 4. The Conference, through ZOOM worked better than our expectations and the inclusivity and accessibility also exceeded our expectations.
- 5. The Conference was able to bring in the politicians relevant to the issues. Labour's Carmel Sepuloni, Marama Davidson, Green Party Co-Leader, Jan Logie, MP Green Party. Paula Tesoriero, Disability Human Rights Commissioner. DWF and disabled women are delighted with the political support they received, as is ZZZZ .
- 6. The relative non-interest by Labour and National politicians, compared to the Green Party's active, ongoing determination to improve the safety of disabled women is a stark warning to disabled people of the lack of visibility and priority our needs are being given. This reflects in NZ signing the CEDAW and CPRD Disability Rights Convention, but even 12+ years after signing the CRPD, these promised "rights" have not been put into practice and legislation.
- 7. The non-disabled members of ZZZZ Committee did not fully understand the concept that there were two important aspects to the Conference.
  - the open part of the conference was designed and intended to communicate to non-abled women, equally with the communications and discussion from and between disabled women. We (disabled women) also need to address the ways intersectionality shows we discriminate against each other, i.e., racism, ageism, classism. Colonialism, transphobia, sanism etc.
  - the closed, disabled women only, part of the conference, designed for us to speak together, re issues and a united disabled women's voice. The many difficulties for disabled women to come together were addressed during the conference

No-one understands Ableism better than disabled women/people and that understanding and healing the hurts of discrimination are an ongoing process.

- 8. The conference was successful in bringing many women, (the Zoom account had to be upgraded due to registration numbers), from across Aotearoa together in a short space of time. It is an ongoing concern, the gatekeeping of service provision and how do we ensure disabled women not only are taught their human rights but how to be aware of conferences and forums that educate and address them.
- 9. The Elephant in the Room: Ableism.
  - Ableism is the discrimination targeted at disabled women/people.
     Discrimination is targeted at many groups and always on a perceived difference to what a society agrees is normal, i.e., better, superior, more priveleged.
  - The differences, e.g., ethnicities, class, age, sex, gender, behind the "ism's" are well understood. Less understood is the similarities of the unaware tactics used to reinforce and continue the discrimination.
  - An example is Colonialism: A Kyriarchal institutionally implemented form of systemic discrimination Maori disabled women live with, a bump that implements racism. It has has 4 common characteristics:
    - 1. Political and legal domination over an alien society.
    - 2. Relations of economic and political dependence.
    - 3. Exploitation.
    - 4. Racial and cultural inequality.

Colonisers impose their way of being and doing, their cultural practices, from attitudes of superiority and practices of privilege, legislated and reinforced via social conditioning and social institutions. Tactics commonly used include:

- a) Divide, conquer and rule: Is about having power over and keeping control. To divide and conquer, when you "feel" you are losing control, you choose a "good" member/s of the marginalised groups, and use them against each other, i.e., the uncontrollable "bad" members. The "good" member/s demonstrates you are working with "those" people and helps you keep control. The opposite of Divide and Conquer is Unite and Build.
- b) Tokenism: Is the practice, within discrimination, where however unconscious, your choosing, (read using) people to create the appearance of diversity when the dynamics of power have not changed one whit! (As above in divide and conquer).
- c) Deflection: Psychological defence system people use to take the blame off themselves. In communication deflection is seen when what is said changes the direction of the conversation. E.g., 1) Your being dramatic, 2) Your blowing things out of proportion, 3) stop being so sensitive, it's not a big deal, 4) your being too emotional, stop doing that.
- d) Denial: an individual and collective fear based, social coping mechanism. A physiological process in our healing system that can manifest when we do not know what to do. E.g., the Holocaust in World War 2, is a social example. At the individual level people say, I didn't know, or I didn't do it etc.

All of these tactics were used through an Ableism lens, before, during and after the Conference on Disability. The DWF women organising the conference supported each other to stay clear, avoid any conflicts and keep the focus on the united voices of disabled women being heard nationally, both on-line at the conference and the conference report being written by the DWF committee members who organised the conference.

DWF committee representatives at a Strategic Planning meeting, early 2021, had to insist the report was the responsibility of the DWF reps and members that had planned and implemented the disabled women's conference. One disabled woman was heard to say Ableism was like trying to wade thru treacle. Even if you get where you want to be, it still sticks to you!

#### Side issues from evaluation

- 1. Lorri had previously run many Conferences, nationally and internationally, using the Speak-Out concept, so was confident it could be applied successfully in the ZZZZ environment. That confidence was well justified.
- 2. The group of people putting together the DWF Conference did not have much experience of working together as a group. Team cohesiveness and effectiveness was not as good as would have been desirable. The diversity within the disability sector, presented more technical communications difficulties than would occur in a non-disabled forum, as well as the straightforward teamwork issues. Our efficiency working together showed about 40% of time, time and energy wasted due to interworking issues. That might sound poor, however, from my previous experience in project planning, I believe that was an **amazingly good performance**, within the circumstances.
- 3. The Conference was possible online thanks to ZOOM. It was very advantageous, as ZOOM accessibility was extremely valuable for most disabled people, financially as well as for physical access reasons. It was fairly high risk, to plan a Conference using so many new technologies that we had little previous experience with. This aspect was very successful, technically as well as for social issues. It forms a technical proof of concept, as much as a social affective communications exercise. This report documents the communication needs in the disability sector and how these techniques were applied in this conference. This is to demonstrate how quickly and easily accessibility can be applied in future forums.
- 5. I (Maria Claire) was at my limits with the time planning spreadsheet. On one occasion the formulae exploded and went crazy. I had to revert to a much earlier version and rebuild it. I then made a mathematical mistake, impossible to correct and it extended the conference by one hour. It inadvertently solved

many small communication and timing problems. With hindsight, this was a very fortunate mistake.

6. It would have been valuable pre-conference, to have had the time, to work on building better understanding and experience in computer communicating, between planning group members. This is for technical issues - sorting compatibility of people.

#### NZ Disability Plan Prepared by non-disabled people

The NZ Disability Plan was prepared solely by able people, much to the disgust of many disabled people. There is a saying used by many different groups, Nothing About Us Without Us. Any policy documents should as far as possible be prepared within the relevant community and make best use of resources within the community. For example, why use able people as researchers, when there are capable disabled researchers who cannot even obtain any employment?

CRPD and ratification...put into recommendations

## **Recommendations** TIPS ON COMBATTING ABLEISM

DO	DON'T
1.Be a staunch ally. Insist on forums, for the voices of marginalised women being heard.	1.Discuss in front of disabled women that you think other issues, e.g., digital technology should take priority.
2. Provide enough funding for all forums, seminars, conferences etc, to be accessible for ALL women, or do not hold them at all. There are no sectors within the women's community, that do not include disabled women. So, include us!	2. Provide funding for a conference on disability then say you do not have enough to pay for NZSL Interpreters so women who are deaf or have hearing difficulties cannot attend, especially when committee members know how much is in the bank accounts.
3. Give control of creating and implementing of the conference to disabled women. We will ask our allies for the assistance we need.	3. Take offence if we remind you, we are able to do it ourselves. There is always different areas where we will ask for assistance.
4. Believe in us. Believe disabled women are able. Able to think, plan, communicate, delegate, implement and do the finances of projects they are organising.	4. Keep control of the funding of projects given to us to organise for our community.
5. Talk to other non-disabled women when feelings of not having control trigger off attitudes, i.e., thoughts, belief's that disabled women are not capable of handling a project.	5. Create our/your reality on your "feelings", that is when ableism kicks in.
6. Remember the Personal is Political and the political is Personal. This means to be effective politically we must continue the personal work. Explore the impact of the attitudes and behaviours of sexism, racism, colonialism, ableism, ageism, transphobia etc, etc. How do you feel.	6. Forget, feelings are for healing. If you ignore them, the brain is unable to process experiences properly. Irrational behaviour will be the result. Discrimination is always irrational. Hurt people, hurt people; healed people, heal people.
7. Understand the tactics of colonisation and how they can be co-opted and used to discriminate against each other.	7. Keep using these tactics to create division amongst disabled women.

8. Listen to disabled women when we ask you not to use our young women, unaware of women's politics or the dynamics of systemic oppression and ableism	8. Use tactics of divide and conquer to take control of disabled women's work.
9. Understand how the tactic of tokenism works.	9. Use a disabled woman who is a non – committee member, nor member of any of the groups represented on the committee as tokenism, so you can say you are working with disabled women.
10. Understand you do this to keep white, middle or owning class privilege, power and control	10. Waste disabled women's time bouncing your guilt and denial off us. Do the personal work. Oppression (the theory) and discrimination (the practice) is intergenerational trauma, we are born into it. If we want to stop the politics of it, we need to understand and heal the personal impact of being discriminated (abused) against and discriminating (abusing) against others.
11. Learn the psychological processes and support each other to heal and undo ableism, (all ism's).	11. Undermine disabled women when they create a forum bigger and better than you thought possible.
12. Understand attempts to take the lead and tell us what to do is ableism.	12. Think that disabled women allowing decisions made by non-disabled women on how to present a disability forum, makes it alright.
13. Understand disabled women's priority is having their collective voice heard. If that means giving others the illusion of control to ensure the forum is not cancelled, that is what we do.	13. Believe if one person threatens to walk out, the conference will not happen. Everyone is dispensable. Creating these forums are a collective effort and not dependent on an individual.
14. know unaware clienting is just as its name suggests. Recommend a good counsellor. We all deserve healing and support.	14. Think creating drama is the role of a good ally. It is not. It is just more unaware clienting and is a focus on self rather than assisting disabled women as an ally.

15. Realise an ally assists as requested and can offer that assistance or not. An ally does not take control.	15. Make your ego more important than disabled women.
16. Understand white economic privilege and discrimination is hierarchical and what is done to us we do/act out on those below us. Women of economic white privilege are used to being vocal and visible. Disabled women are the bottom of the hierarchy and lack a voice and are invisible	16. Use us as a token on your committees and make us invisible, except when you want to display your diversity.
17. Know we are women and we want to work with other women on an equal and equitable basis.	17. Think non-disabled women can keep determining what that equal and equitable basis looks like. Disabled women have seen historically how inclusive and accessible that is.
18. Know disabled women can tell you what is needed to create that equity and equality, including universal design and universal services. Listen to us and let us lead the way.	18. Take the credit for providing the funding or the donor when outside sources offer to support disabled women to create an accessible conference that deaf women.
19. Hand over the financial breakdown of funds allocated for the conference and show how non-disabled women allocated the money.	19. Ever with-hold and control funding allocated to an event disabled women are organising.
20. Understand, showing the financial break-down of allocated funds and donor sources allows disabled women to show the financial viability of online accessible conferences IN THE REPORT.	20. Think it is appropriate for non-disabled women to have control of a disability report especially do not use the tactics of deflection and tokenism to justify undermining disabled women?

- 21. Know it is important to have a **committee only debrief** to address the successes and the challenges of implementing projects like seminars and conferences. Refusing to debrief when disabled women request, is ableism
- 21. Try to bring non-committee members to avoid addressing the inter committee dynamics of discrimination. When disabled women want to address ableism, they are doing the committee a favour and it is important to listen and resolve intersectional discrimination in the women's community.
- 22. Understand that disabled women know these attitudes and actions are unconsciousness and ALL women's groups need to address these issues as teamwork training.
- 22. Think, the above only applies to disabled women, you can replace us with any of the many marginalised women's communities that need allies to include them visibly in the women's movement and create a level playing field.
- 1) One organiser was concerned that most disabled people were very unaware of the Social Model of Disability and the relevant UN Declarations. Especially of the day-to-day implications of lack of these "rights" being applied in legislation in NZ. This is a huge topic requiring a lot of communication. This general lack of disabled issues understanding, education and discussion will impede disabled women having visibility and a voice.

#### **Recommendation 1:**

A] Lobby and support disabled peoples demand for a Ministry of Disabled People.

B]

Step 1: Respect the dignity of disabled women.

Step 2: Listen ... don't talk, just listen.

Step 3: Believe in us.

Step 4: Trust in our abilities.

Step 5: Be good allies. Provide support if we ask for it. If unsure ask us. Do not do less or more than asked to do, (doing less is undermining and doing more is controlling). Understand and help us end division and control, i.e., them and us using power over versus mana, power with, tokenism, gatekeeping especially in the service provider sector.

C1

Lobby M.P.'s, Government and United Nations on the lack of implementation of Article 33 ??? of the CRPD. The agreement for government to fund teaching disabled women their human rights has never happened in an ongoing, systematic structure, e.g.:

- All service provision funding could have attached the requirement to teach the CRPD, CEDAW and Family/Whanau Violence Legislation 2018; be it housing, work, support staff, education etc., providers.
- Disability advocates, working in pairs at a ratio of 2 disabled women advocates to 50 clients??, included in SAFA within all service provision organisations, selected, trained and supported by Ministry of & by disabled people.
- Can, as part of the job description, be responsible for ensuring the service provider provides ongoing training in the Social/Human Rights Model of Disability and support the implementation of said rights in the disabled persons life
- 2) There was also a feeling among some ZZZZ Committee members that it might be inappropriate that disabled women were getting the spotlight in this Conference, when many years had gone by and ZZZZ had been unable to obtain improvements in the social conditions for Maori women.

#### **Recommendation 2:**

- Women's organisations implement training for members re Cycle of Systemic Discrimination and Intersectionality and the tactics used to implement it and tactics to reinforce and continue it, i.e., the Political.
- We emphasise the why (it is important) and how we heal the hurts of systemic discrimination, i.e., the Personal.
- We remind each other it is not a competition. The only winners if we turn on each other and play ..." who's been hurt the most", is the social system that installs systemic discrimination.
- Pain is pain and Hurt People, Hurt People and Healed People, Heal People. We all deserve to heal.
- To focus on the Political and ignore the Personal, disempowers us and our communities and feeds and continues the Cycle.
- Intergenerational Trauma teaches us the unhealed hurts get repeated generation after generation, until healed and resolved.
- Political women's groups have a responsibility to lead the way and support and empower the most marginalised women's voice first.
- Team development exercises, listening and learning about intersectional identities and communities, to be part of agency/organisational policy. This is an extremely important investment, to develop group strength, trust and capability. This needs strong lobbying work in future. It is difficult, if not impossible to stop discrimination if we do not understand the attitudes, language and actions we use to do it, unawarely against each other.

The NZ Government signed the CRPD (Convention for the Rights of Persons with Disabilities) in 2006. In 2008 our Government ratified the CRPD

#### **Political Panel Recommendations**

**Question 1:** Panellists responses re solutions for creating a level playing field for ALL women.

**Facilitator Jan Logie:** ..." that the mainstream response of relying on a call to the police does not work for many disabled women. We need to create new pathways for people to be able to disclose and get help." ... "we got a small amount of funding for prevention work in marginalised communities including disabled people. The intention" ... "to build relationships between DPO's and officials" ... "to start that work on planning how we develop those pathways" ... "it has been surprising to me how hard it has been to get that moving. I thought it would be a quick and easy solution" ... "It wasn't" ...

**Comment:** Good allies are amazing, just telling them doesn't work, they learn the hard way. The tenacity of those who stick with us makes a difference!

**Recommendations:** SAFA programmes continue to be developed and funded and disabled women advocates (see appendix) become part of SAFA programme and for all service provision agencies/organisations.

 Review of guidelines for DPO's. It has been many years since policy and guidelines for what constitutes a DPO was written. We now have a better idea on what works and what does not. Tighter guidelines are necessary to prevent non-disabled people becoming the voice of disabled people.

**Facilitator Jan Logie:** ..." Our services mainstream family violence services have not been resourced and are not, in most cases accessible" ...

AND (Family Violence Act 2018)

... "When we put the changes into legislation" ... "the system thought putting it into law would make it happen. That they didn't need to do the work – really specific work within their own agencies on being able to implement those protections for disabled people" ...

**Comment:** A solution to ableism and family violence service provision can be resources but resources are not the problem.

The problem is in attitudes and actions, not resources So many disabled women have worked for so many decades for access to safety and support re domestic violence. Service provision in these areas engage discuss, write reports, discuss some more, write more reports and pay their mortgages while disabled women continue to endure the violence or die. Agencies use government funding and when government increase funding, disabled women knows where it does not go. Services fund raise to provide extra services in many different area .... but rarely anything to make what non-disabled women take for granted, accessible to disabled women.

#### **Recommendations:**

- Checklist on what is accessibility provided. (see appendix)
- All future government funding contingent on 25% used to create accessibility in the different ways required, over next 2 years.
- After 2 years funding only provided to services that meet accessibility criteria, drawn up by disabled people.

Generations of experience tell us that sometimes the only way to create inclusion, is legislation

Ronelle: .... "disability is not a Maori construct" ...

**Comment:** Similar comments are repeated by Maori and Pasifika disabled women/people

**Recommendations:** Provide forums to explore what this has meant, does mean and can become for disabled people and society.

**Martine:** ..." If we are not at the table, we are going to be on the menu." ... "whatever analogy we need to use, we've got a lot of history of people speaking on our behalf and it's not working" ...

"You do not see non-Maori people and non-Pacifica people hopefully, speaking at government, legal and other levels on behalf of these communities. But you still have heaps and heaps of officials and non-disabled people who are speaking on our behalf" ....

**Comment:** Not just speaking, deciding acting and doing. At core of ableism/discrimination is the belief the disabled are not able! Of course, the opposite is the reality

**Recommendations:** That education, discussions are held by disabled women, for disabled women/people on the understanding of the groups represented within:

- the disability sector, e.g., disabled women/people, whanau, service providers.
- The voice of disabled people, i.e., disabled people. As for Maori, Pacifica, Women, Trans, and other marginalised groups, to speak on what it is to be disabled, you must be disabled

- Disabled Advocates are built into the system, to support disabled women in different areas.
- E.g., disabled children and women/people with complex disabilities living with family. Advocates to support the disabled person, advocates to support family ... a connected system
- For disabled women who receive services from a service provider.
- Disabled women living in residential care and nursing homes etc.

**Paula:** said on creating a level playing field one of the biggest challenges ..."is actually knowing how uneven the field is to begin with and how big the bumps are along the way" ...

..." a solution that we need to look at is ensuring that data can be desegregated by gender and by disability" ...

**Comment:** Love this comment. Disabled women know how true this is, yet if we had to describe why it is true, it becomes very difficult to provide the whole picture.

#### Recommendations:

- Nationwide implementation for disability data collection, desegregated by disability and gender.
- Action on recommendations from government reports to date.
- Plan is created to outline the bumps as disabled women experience them and solutions from disabled women, prioritised by disabled women

**Paula:** Another solution would be to ensure that we specifically seek the voices and experiences of disabled women through resourcing a women's DPO, if that's what disabled women want. We'll talk more about that later.

#### AND

some of these AMAZING disabled wahine need to get into parliament and help our non-disabled allies strengthen all our work and outcomes.

**Comment**: Yes and Yes! That barriers are explored and removed to enable the voice of disabled women to be at the political table

#### **Recommendation:**

- Disabled women continue these discussions with each other, allies, Human Rights Commission and Government until this happens.
- Disabled people choose and campaign to have disabled M.P's.

**Victoria:** ..." that we collectively advocate for quotas for disabled people to be employed in the public service" ... "Getting us in there means we are more present. We are having more influence and impact

**Comment:** Yes, a simple elegant solution where government can model the workplace reflecting society.

**Recommendations:** That for every 100 people employed in public sector, government employ 24 disabled people and 12 of every 24 disabled people employed must be women

**Paula:** ..." disabled women told the Human Rights Commission in 2018 that violence was their top concern. We know that we still have legislation that allows medical procedures to be conducted on disabled women without their consent" ...

**Comment:** Disabled women have been advocating for decades to legislate sterilisation for disabled female children as a criminal offence as mandated by the United Nations Convention Against Torture and other Inhumane Treatment (UN CAT). CAT creates international law that NZ has agreed to implement into national law and failed to do so. Intersex babies are also protected by this and other conventions internationally but not protected in Aotearoa. Refusing to continue forcing the binary system on babies at birth can prevent disability happening to many intersex children

**Recommendations:** NZ Government take immediate action to protect babies and children from these practices by making them illegal in NZ, in line with the international agreements and laws they have signed and ratified.

Jan: ... "We have a question asking if we can stop calling people "carers" and saying that's not really the case. The role is personal assistant or support staff. Even for family paid in that role, it becomes a role of paid assistant amongst other roles of parents, friend, etcetera" ...

**Comment:** Language is not static, it shifts and changes in meaning and context, especially the language of discrimination. This language evolves in impact and meaning. To much of the language in the disability sector dis-ables and disempowers disabled women, children and men.

**Recommendations:** Disabled women hold bi/tri annual hui's that focus on language. That government update the language used in relation to disability as requested, thru the Ministry Of & By Disabled People.

Scrap Wage Exemption Act 1983, which allows employers to pay "wages" below the minimum wage.

#### Appendix A Speakout Themes explained in more detail

This appendix gives a brief explanation of several of the common themes that came out in the Speakout.

They are all covered in more detail, with more discussion about why they are impactful and with several examples, in The Introduction to Disability Issues. Additionally, several keywords are boldened and they too are further explained in The Introduction to Disability Issues.

This chapter highlights the extent to which the disabled person makes and applies their choices. These choices and reactions may appear strange or inexplicable to able people, but are generally due to the practical realities faced by disabled people in our wider culture and the realities which develop the various disabled cultures.

Until you have experienced these in real life, it is quite challenging to learn the various disabled cultures. But they are there for very good reasons......

## **Identification**

I choose to identify first and foremost as a woman, then as ethnic group and then as disabled.

Many aspects of identification are a voluntary choice. I may choose to not acknowledge some aspects of my identity, perhaps due to stigmatising of this condition by society or religious persecution.

**Prejudice** is treating somebody according to unfounded assumptions about them, not according to the actual capabilities of the individual person.

A disability may be **visible**, so that I have few options to try to conceal it. A walking stick may be thrown away, but at the risk of falling onto a concrete pavement.

If I choose to hide an **invisible disability**, then I am likely denying myself any support, in the hope to avoid the associated **social stigma**.

If circumstances go against me, this disability may be exposed anyway, against my efforts to conceal it. By choosing to hide or not disclose the disability, it is likely that I will slowly **internalise the societal oppression** and suffer accumulating damage to my mental health, in addition to the problems caused by lack of social supports that might be available. When they choose or are forced to come out, the accumulated mental health problems may take some years to be properly treated. If left untreated, they may result in suicide. In

many cases, once exposed or outed, it is impossible or difficult to escape from the stigma associated.

These are harsh choices to be forced to make. A person may be in **stealth** in some environments and open about their disability in other environments. This may be tricky to manage, if the two environments mix together, at some time.

Although at the moment, I may prioritise my identifications, circumstances can change and I may be forced to reprioritise my identifications. Other people may just consider that their disabilities are all equal and no prioritising is appropriate or necessary.

The priority may show up one way, in one environment and differently in other environments, depending on relative pressures and prejudices.

As a deaf person, if I don't acknowledge my deafness, I essentially deny myself help from others, when I don't hear a word. I don't always know when I may have misheard a word, so trying to live in stealth may be disadvantageous or even dangerous in some situations. It might just be that a noisy car just went past, or a door slammed shut.

**Invisible disabilities** include deafness, dyslexia, colour blindness, autism, intellectual disabilities, ...

If a person denies their disability, they are denying themselves support from groups of similarly disabled people. This might sound surprising, but many disabilities progress slowly and it is easy to be unaware of how much problem is resulting. It may also deny them better understanding, if they are unaware of the social and **cultural aspects** of the disability.

Hard of hearing people have quite a different **culture** to Totally Deaf people. This may create difficulties, as many people progress slowly from Hard of Hearing, to Total Deafness. As a result, unless they learn the culture for total deafness, they may be disadvantaged by remaining with a Hard of Hearing culture. It does take quite a lot of effort, to learn the new culture and to a moderate extent, unlearn the earlier culture.

## To be heard

Most disabled people experience restricted listening and the remaining gap is filled with prejudicial assumptions.

I just want a life, like the people around me. They say I can't have this because they think I am incapable. I want people to actually listen and hear what I say.

I want access to support services that actually listen to me, that meet our individual needs. That don't just fail us and then limit us from living our aspirations for our life.

We are particularly vulnerable to not being listened to, when we make a complaint. Too often we are glossed over and our complaint is not listened to, not investigated and our interests are left unprotected.

It is true that to act to give protection is often more complex than for nondisabled people and more costly. But there is no budget for protecting us and as a result too often no action is taken to protect us.

But that is no excuse to fail totally to protect our interests.

# **English Language barely supports our individuality**

English language lacks words that respect our individuality and individual culture. I may sometimes enjoy social respect for my choice of pronouns as "they".

Among my wider family, I don't have a word for me that communicates me as aunty or uncle.

But at the local hospital, I am reduced to "other". By choosing this lazy grouping of medical conditions, the DHBs prioritise heterosexual identities and reduce all other conditions, to a grab bag of "other". This means that they substantially refuse to provide services on a similar basis, as they do for heterosexual male or female.

As a result, all of the "others" receive degenerate, inadequate medical services. Doctors do not have satisfactory training, to deliver acceptable, safe, medical treatments, for the "others".

Then the social disrespect is the icing on this maltreatment cake.

## Disabled people shouldn't exist at all....

Disabled people should happily accept euthanasia by the advantaged majority. Alternatively, selective abortion or eugenics....

This simple and easy approach would deny the world the services of Stephen Hawking astrophysicist, Helen Keller human rights advocate, Beethoven music composer.....

This may sound horrific and it should never occur at all. But in reality, sex selective abortions have now prevented the birth of over half a billion girls, mainly in China and India. Some genetic conditions may be detected early during a pregnancy and this allows the parents the option of an abortion.

These attitudes are **invalidation** of all disabled people to the extreme, invalidation of women too.

This is not just patronising, it is suggesting that you have no right at all, to exist on this Earth.

## **Intersections**

Where two disabilities apply simultaneously, the situation quickly gets more complex.

Usually two individual cultures are involved. The intersection of two disabilities might not create problems, but in most situations the intersection will create additional, often serious problems.

Consider being blind and deaf from birth or early childhood. It is obvious that the intersection adds very serious problems.

Most benefit systems provide a benefit to cover only the most serious disability. There is no further provision for any additional disability. This is a highly prejudicial situation, as the intersection only adds additional problems. The person with both disabilities receives only a benefit to cover the most serious disability. A high proportion of disabled people have two or more disabilities. Their only hope, might be to be born again?

## Respect as a human being

To feel supported is quite sensitive to cultural differences. This is not to say that non-white cultures are too sensitive. On the contrary, non-white cultures are regularly ignored and invalidated within NZ's WINZ system. Failures to provide multicultural respect, end up being active and potent **microaggressions.** 

## **Inclusion and Exclusion**

Inability to talk as fast as most people, often leads people to wrongly judge me as intellectually disabled. Often they will direct a question for which I should

reply, to the obviously abled people with me. This invalidates me and humiliates me. Perhaps the able person with me, waits for me to slowly answer, sometimes they don't.

People may be excluded for their inability to climb steps, or the width of their wheelchair stops them being able to get past some unthinking barrier. The distance from disabled parking may be too great, to allow practical access.

Exclusion may be due to assumptions about ability to hear instructions about how to gain access. If a hearing person is within the group, they can gain access. If not, then the group may be unable to gain access into the building, despite having arrived at the doorstep. The barrier may be only to Hard of Hearing culture, but that may end up totally barring access even for Totally Deaf people.

Exclusion may be that the benefit paid allows for accommodation and food, but what is over is insufficient to be able to pay for the necessary specialist transport to be able to participate in social events. This factor severely restricts social participation by almost all non working disabled people. The UN Convention on Disability includes social participation as a necessary element, but although NZ has committed to support this, the necessary legislation hasn't been prepared in the 15 years since CRPD was signed. At present there is no indication that such legislation will ever be signed into NZ law. It leaves some disabled people in a situation more akin to zoo care, fed and watered but still living in a locked, concrete and steel bar cage.

Deaf/Hard of Hearing people and LGBTIQ people have many separate **cultures**. Even though some thought may have been given to LGBTIQ accessibility, the end result may still be inaccessibility for one or several sections of LGBTIQ or deaf people. They may get in the door but are so microaggressed, that they choose to leave, even after having successfully got in the door and vow never to return again.

## **Feeling of Community**

This feeling is usually taken for granted by dominant groups within society, eg heterosexual men and women.

But many minority groups can only relax and let down their guard in a small number of social situations. If they are living in **stealth**, these may be few and far between. In some cases, a moderate feeling of community may be experienced within adjacent social groups, eg a transperson may appreciate being among other LGBTIQ people, or a deaf person among hard of hearing

people. Sometimes this works well and sometimes it still leaves a feeling of lack of community.

It may be working well and change in a moment. A cruel joke may suddenly turn an environment exclusionary and cold. The end result is partial and unreliable support.

To be strong as women in contributing to the communities that we are part off. Overall, I think that it really came through about just our being able to be ourselves. Just be accepted for who we are.

We heard about various barriers and abuse in a lot of situations. Of course, that's all about the power dynamics that are at play. We just want to be accepted for who we are as women and to be seen as women. So, thank you for that. I have great hopes for what we can achieve together.

It is often said by privileged majority people, just wait patiently until the Government can afford better support. Just wait at the back of the line.....

Dr. Martin Luther King published his book Why We Can't Wait, in 1964. Although there have been some relatively minor improvements in respect for African american's human rights, the overall situation is little different today, than it was in 1964. His book can be read (free) at Archive.org:

https://archive.org/details/whywecantwait00king

In choosing to speak out, our disabled speakers have left themselves open to critical comment or humiliation by people who have failed to understand them. This may be due to ignorance about disability, or it may be due to malice on the part of commenters. This willingness to speak out is in the hope to build better community understanding. Our schools are generally doing well in teaching these sorts of understanding and community care.

I am sure that we have all read newspaper accounts of rape victims (both women and men) being handled disrespectfully by police and other service agencies. It has taken a long time (two generations) to improve these services quality of support. And we still need to make further improvements. It does take a lot of effort to build better understanding, across many types of situations.

#### Appendix B Choosing to Listen – Listening through guilt, pain and privilege

**Advocates** and **Allies** do need to choose to be actively involved. Passive listening is rarely of much help to advocate for a marginalised person.

**Teamwork** requires significant mutual understanding. In a cross-cultural context, this is much more complex than in a mono-cultural situation.

When we consider all of the different types of culture that exist within our society, ethnic, language, disability, skin colour, religion and others too, not many relationships are actually mono-cultural.

Many relationships may appear to a glance, to be mono-cultural, but a more careful look at the relationship in most cases will disclose multi-cultural issues that are present. In some situations, the cultural disparity may have no impact. It requires a lot of cultural understanding to see ahead how issues will impact onto a working relationship.

The impression of NZ being a mono-cultural society is just a lazy self-delusion, by people who are not prepared to put in the effort to build reliable and safe relationships.

To be effective allies or advocates, we need to be sensitive to these issues and active in addressing these issues as they arise.

Listening to marginalised people will usually involve actively listening to stories which include suffering and pain, to walk in their shoes for a little time. This does take willingness to feel their pain, to understand it and understand the implications and consequences that flow from it.

It opens the question, could I bear their life, if I was dropped into that situation? This is a large challenge, if we wish to be useful allies or advocates. We should know that in real life, aging could drop us into some of these circumstances. This is a scary prospect and opens up our **fear**. Fear is a potent barrier to accurate communications, especially listening.

If we are clearly different to them, do we have the patience to listen through their experiences? Do we **trust** them enough, to invest our time into helping someone, quite different to ourself?

## Elvis Presley song - If you could see you through my eyes

If I could be you, if you could be me For just one hour If we could find a way To get inside each other's mind, uh huh

If you could see you through my eyes Instead of your ego I believe you'd be, I believe you'd be Surprised to see That you've been blind, uh huh

Walk a mile in my shoes Just walk a mile in my shoes And before you abuse, criticize and accuse Just walk a mile in my shoes

Now, if we spend the day Throwing stones at one another 'Cause I don't think, 'cause I don't think Or wear my hair same way you do, uh huh

Well, I may be common people But I'm your brother And when you strike out through tryna hurt me It's hurtin' you, Lord have mercy

Walk a mile in my shoes Just walk a mile in my shoes Yeah, before you abuse, criticize and accuse Just walk a mile in my shoes

Now, there are people on reservations And out in the ghetto And brother, there But for the grace of God Go you and I, uh huh

Uh, if I only had the wings Of a little angel Don't you know I'd fly To the top of the mountain And then I'd cry, cry, cry

Walk a mile in my shoes Just walk a mile in my shoes Yeah, before you abuse, criticize and accuse Walk a mile in my shoes

Walk a mile in my shoes Just walk a mile in my shoes Yeah, before you abuse, criticize and accuse Walk a mile in my shoes

Source: <u>LyricFind</u> Songwriters: Joe South

Walk a Mile in My Shoes lyrics © Concord Music Publishing LLC, Peermusic Publishing

## What Happens When You Tell Your Story and I Tell Mine?

Sometimes, empathy isn't enough. New research reveals how taking and giving perspectives can help us to bridge our differences.

BY ZAID JILANI | JANUARY 9, 2020

https://greatergood.berkeley.edu/article/item/What\_Happens\_When\_You\_Tell\_Your\_Story\_and\_Tell\_Mine#thank-influence

As a white man who grew up in Texas, John Howard Griffin was curious about the lives of African Americans who lived under America's Jim Crow system in the late 1950s. So, he embarked on a <u>bold experiment</u>. He decided to darken his skin, live as a black man, and write a book informing his fellow white citizens about how it feels to be on the other side of the racial divide.

"How else except by becoming a Negro could a white man hope to learn the truth?" he wrote on the <u>first page</u> of the book, titled <u>Black Like Me</u>. "The Southern Negro will not tell the white man the truth. He long ago learned that if he speaks a truth unpleasing to the white, the white will make life miserable for him. The only way I could see to bridge the gap between us was to become a Negro." Published in 1961, *Black Like Me* went on to sell 10 million copies all over the world.



John Howard Griffin, author of Black Like Me, in both his guises.

Psychologists have a name for Griffin's experiment: perspective taking, which involves being able to see the point of view of someone you normally consider to be part of an outgroup. Griffin decided he needed to be able to see the world from the perspective of a black man in order to more fully understand African Americans and their struggle for civil rights.

But Griffin didn't just take someone else's perspective. He also *gave* a perspective to countless white Americans who had never considered what it was like to live under America's system of anti-black discrimination. Research is finding that this "perspective giving"—being able to offer another point of view, especially if you're part of an outgroup—can be just as important to social change as perspective taking.

Of course, Black Like Me could never supplant the voices of African Americans themselves. As activist Stokely Carmichael (later known as Kwame Ture) said at the time, Black Like Me "is an excellent book—for whites." According to Griffin himself, his memoir was meant only as a bridge for European Americans who had trouble listening to African Americans, in hopes that it could open their hearts and minds to the experiences of other people. His book stands today as an extraordinary experiment in both perspective taking and perspective giving. Together, they're powerful tools for bridging our differences, particularly between groups that may not have an equal power dynamic. When a perspective has been marginalized by the larger society, says Beyond Conflict Innovation Lab lead scientist Emile Bruneau, it's important to allow that one to come forward first—and for members of the dominant group to then try to take it in before giving their own. Bruneau and other researchers are studying perspective taking and perspective giving in domestic and international contexts. What they're finding could help more Americans negotiate their differences.

## Empathy isn't enough

Perspective taking is not precisely the same thing as empathy—and if you're trying to build bridges between different groups, it's important to understand the difference. We often think about emotional empathy as being able to feel someone else's emotions, whether it's the pain of a friend or the joy of a family member. But empathy has its limits.

In late 2019, a group of researchers <u>set out to test</u> the impact of empathy on polarization between Democrats and Republicans. First, they used survey data gathered in 2016 to see how individuals with greater empathic concern would feel toward partisans on the other side, using measures of social distance, such as how upset they would feel if a family member married a member of the opposite party. The researchers

also ran experiments to measure how empathic concern affects partisan bias in situations like wanting to censor a speaker from the opposite political side.



Elizabeth Simas, associate professor at the University of Houston.

While we might hope that empathy would fuel tolerance, that's not what this study found. According to lead author Elizabeth Simas, an associate professor at the University of Houston, empathic concern did seem to be associated with less discomfort with the other side—but at the same time, it came with more negative feelings. Those higher in empathic concern expressed a greater desire to censor out-party speakers, as well as "more schadenfreude when a person was injured trying to hear a speaker from the opposite party."

That means that emotional empathy—trying to feel what someone else is feeling—was not found to be particularly useful in reducing polarization. In fact, it appeared to make things worse.

Why? One of the problems with emotional empathy is that we tend to feel it more towards ingroups—people like us and people we can relate to—than to outgroups, who seem so different from us. If our ingroup is attacked by an outgroup, empathic concern doesn't necessarily help. But we shouldn't confuse emotional empathy, which is often based on gut responses, with perspective taking, which asks us to do the *conscious* and intellectual work of taking the viewpoint of our opponents, even if we have no emotional warmth towards them.

"Empathic concern is an emotional form of empathy, while perspective taking is a more cognitive form of empathy," says Simas. "That is, empathic concern involves reacting to another's suffering with feelings of sympathy or compassion. In contrast, perspective taking does not involve an emotional reaction to another person's situation." The goal isn't to feel what they're feeling. Instead, it's to understand why they feel the way they do.

That doesn't mean that empathy is useless. It can help us grow closer to people, especially our loved ones. But we should be wary of its downsides, and be cognizant of the reality that sometimes it is more appropriate to engage in perspective taking instead. This seems to be particularly true of trying to understand our opponents.

# Perspectives across borders

Many of our conflicts take place across international borders, which divide people into warring or skeptical camps. But what if we were able to see the situation from the point of view of adversaries?

That's the question Bruneau and MIT neuroscientist Rebecca Saxe sought to answer in a 2012 study that looked at how perspective taking and perspective giving can help bridge divides.



University of Pennsylvania psychologist Emile Bruneau.

Bruneau says he originally became interested in the topic when he was teaching high school many years ago. He'd host "dialogue sessions" between white and non-white kids.

"And what seemed to happen is the white kids would take a lot from these experiences, because they would be exposed to perspectives they'd never considered before," says Bruneau. But the non-white kids (who were a minority in this school) would generally gain less from the experience, perhaps because they were in an environment where they were already exposed to majority points of view constantly.

So, Bruneau developed a hypothesis that perspective taking "wouldn't really work for members of a minority or marginalized group." But he also came to wonder if combining perspective taking with perspective giving could help bridge divides between members of majority and minority groups.

In their study, Bruneau and Saxe brought together two pairs of groups across international borders. They took Mexican immigrants and white Americans, and Israelis and Palestinians, and put them through a set of experiments that involved both perspective taking and perspective giving.

In the Middle East, Bruneau was shocked at how little interaction there was between the groups. "The first [Palestinian participant] after the study came up and thanked me and said, 'I'd never had the opportunity to talk with an Israeli before," he says. "That was shocking to me just because we were standing in Ramallah, which is eight miles away from Israel."

With both pairs of groups, the researchers found that dominant group attitudes toward the minority improved significantly after hearing their perspective. Meanwhile, the chance to give their perspective seemed to help the minority group members to see the majority in a more positive light.

The fact that both experiments showed similar results despite different cultural and geopolitical contexts suggests the one-two punch of perspective giving and perspective taking can prove effective across divides in a multitude of situations.

Although Bruneau's research suggests that perspective giving is more valuable for minority or marginalized groups while perspective taking is more valuable for majority or dominant groups, he says that in practice, it's probably best for participants to do both—but it's the group with less social power who should go first. "That serves the psychological needs of both sides," he says.

# Giving and taking

Organizations in the United States are putting these scientific insights to work in closing America's political divide.

When Nashville, Tennessee, found itself divided over rising immigration and diversity, the Tennessee Immigrant and Refugee Rights Coalition created <u>Welcoming Tennessee</u>, which set out on an ambitious project aimed at integrating the immigrant population into the region, largely by sharing stories and perspectives.



At "Refugee Day on the HIII," members of the Tennessee Immigrant and Refugee Rights Coalition take their stories directly to state legislators.

Thanks to the work of Welcoming Tennessee, the city's social and political climate dramatically changed in a matter of a few years. In 2009, campaigners pushed a ballot initiative that would have required all government documents to be conducted in English only. But thanks partly to the work of Welcoming Tennessee, the ballot measure failed, with 57 percent of voters coming out against it. In 2014, Nashville opened an Office of New Americans, specifically tasked with working with immigrants and refugees to help them acclimate to life in the city. One of the programs the city runs now dispatches Parent Ambassadors—volunteers who come from the same country or share a native language—to work with immigrant families and help them navigate the school system.

This local work was so successful that the effort went nationwide. Since 2009, Welcoming America has been working with communities all over the country to help them overcome skepticism towards immigrants and refugees.

Welcoming America taps local community figures—municipal officials, civil society leaders, and refugees and immigrants themselves—to help move communities across what the organization calls the "welcoming spectrum." The <u>goal</u> is to bring communities from "fearful" to "tolerant" to, finally, "welcoming."

A key part of this work is empowering immigrants and refugees to tell their own story to elected officials and others.

For instance, their <u>One Region Initiative</u>—which aims to build a more inclusive culture for immigrants and refugees in the Atlanta, Georgia, area—held a series of listening sessions that included 142 participants, who ranged from documented and undocumented immigrants to refugees to U.S.-born citizens. These sessions allowed the organization to directly hear from people whose lives were affected by their policymaking.

Welcoming America identified several key concerns from these sessions, with the top two being a lack of English proficiency and fear of deportation. The listening sessions also generated ideas for a plan of action, which included a question-and-answer session with local elected officials, as well as more conversations across racial divides.

Rachel Peric, the executive director of Welcoming America, says that the events help "people understand that while they may share a common humanity, their experiences may be different, and I think those stories and the active listening to those stories sets the stage for policymakers to understand how people are differently impacted by all kinds of policy."

If you would like to practice the skill of taking in other people's perspectives, Welcoming America is a great place to start. We have also profiled other organizations that will allow you to practice this skill, from the <a href="One America Movement">One America Movement</a>, which facilitates dialogue between political partisans, to the <a href="website AllSides">website AllSides</a>, which is designed to allow you to see how people across the political spectrum view news events. If John Griffin could risk discrimination, expulsion, or worse to see how his fellow Americans of African descent lived their lives, we should be

willing to step out of our comfort zones and consider the power of perspective taking. And although we don't live in the mid-20th century American South and the era of Jim Crow, the lessons of Griffin's bold experiment are relevant in all sorts of contexts. As he writes in a 1979 look back on *Black Like Me*:

All human beings face the same fundamental problems of loving and of suffering, of striving toward human aspirations for themselves and their children, of simply being and inevitably dying. These are the basic truths in all people, the common denominators of all cultures and all races and all ethnic categories...

I believe that before we can truly dialogue with one another we must first perceive intellectually, and then at the profoundest emotional level, that there is no Other—that the Other is simply Oneself in all the significant essentials.

This alone is the key that can unlock the prison of culture.

# About the Author



## Zaid Jilani

**Zaid Jilani** is *Greater Good*'s <u>Bridging Differences</u> Writing Fellow. A journalist originally from Atlanta, he has worked as a reporter for *The Intercept* and as a reporter-blogger for ThinkProgress, United Republic, the Progressive Change Campaign Committee, and *Alternet*.

# Rereading Black Like Me by John Howard Griffin

Fifty years after John Howard Griffin darkened his skin and travelled through the segregated US south, his record of the fear and prejudice he experienced is still resonant



A universal story ... a scene from *Black Like Me*, directed by Carl Lerner, 1964. Photograph: The Hill Top Company/Sportsphoto Ltd/Allstar

# Sarfraz Manzoor

Thu 27 Oct 2011 09.00 BST

https://www.theguardian.com/books/2011/oct/27/black-like-me-john-howard-griffin

ne day in 1964 <u>John Howard Griffin</u>, a 44-year-old Texan journalist

and novelist, was standing by the side of the road in Mississippi with a flat tyre. He saw a group of men approaching him. Griffin assumed the men were heading over to assist him but instead they dragged him away from his car and proceeded to beat him violently with chains before leaving him for dead. It took Griffin five months to recover from the assault. The attack was not random; the beating represented a particularly brutal form of literary criticism: Griffin was being punished for having written a book. *Black Like Me*, the book in question, had been published three years earlier in November 1961 and it had led to its author being both venerated and vilified. Griffin, a lantern-jawed and chestnut-haired white man, deliberately darkened his skin and spent six weeks travelling through the harshly segregated southern states of America, revisiting cities he knew intimately, in the guise of a black man. On the opening page Griffin set out the question he was attempting to answer: "What is it like to experience

discrimination based on skin colour, something over which one has no control?" No white man could, he reasoned, truly understand what it was like to be black, because black people would never tell the truth to outsiders. "The only way I could see to bridge the gap between us was to become a Negro," Griffin writes. "I decided I would do this."

He visits a dermatologist who prescribes medication usually given to victims of vitiligo (a disease that causes white spots to appear on the patient's skin) and he supplements the medication with sessions under a sun-lamp and by shaving his hair and rubbing a stain into his skin. In one of the most powerful passages in the book Griffin describes the shock of seeing his new self in the mirror for the first time. "In the flood of light against white tile, the face and shoulders of a stranger," he writes, "a fierce, bald, very dark Negro glared at me from the glass. He in no way resembled me ... I had expected to see myself disguised, but this was something else. I was imprisoned in the flesh of an utter stranger, an unsympathetic one with whom I had no kinship ... I looked into the mirror and saw reflected nothing of the white John Griffin's past. No, the reflections led back to Africa, back to the shanty and the ghetto, back to the fruitless struggles against the mark of blackness."

Startled by how little of himself he recognises, Griffin sets off on his journey and is further shocked by how little he recognises of his own country: the man who shines his shoes every day does not recognise him, the restaurants he usually eats in are no longer open to him, and he has to plan ahead if he wants to use the bathroom or drink from a water fountain. White folks either treat him with extravagant politeness – when they are on the hunt for black girls or they want to inquire about his sex life - or they give him what Griffin describes as "the hate stare". "Nothing can describe the withering horror of this," he writes, "you feel lost, sick at heart before such unmasked hatred, not so much because it threatens you as because it shows humans in such an inhuman light. You see a kind of insanity, something so obscene the very obscenity of it terrifies you. I felt like saying 'What in God's name are you doing to yourself?" Being exposed to the hate stare, witnessing racism from the other side, leaves Griffin sad and angry; he grieves at how "my own people could give the hate stare, could shrivel men's souls, could deprive humans of rights they unhesitatingly accord their livestock". He concludes that "the Negro is treated not even as a second-class citizen but as a tenth-class one."

Griffin's outrage at this injustice was rooted in his own life. He was studying in France at the outbreak of the second world war and joined the French resistance, helping to smuggle Jewish children to Britain. Having witnessed the consequences of racism against Jews he became more sensitive to the plight of black people in America. Griffin had been temporarily blinded during the war after being blasted with shrapnel. He recovered his sight two years before embarking on the journey he described in *Black Like Me*, and the book can be read as a reaction to the lessons he learnt while sightless. "The blind," he would later

write, "can only see the heart and intelligence of a man, and nothing in these things indicates in the slightest whether a man is white or black." *Black Like Me* was Griffin's effort to persuade America to open its eyes. The first extracts from the book were published by Sepia magazine, and immediately he found himself the target of hostile attention. He received death threats, and an effigy of him was hung in Dallas, his home town, prompting Griffin and his family to go into exile in Mexico, where he did further work on the book. When it was published, he criss-crossed the country delivering lectures on his experiences; *Black Like Me* was translated into 14 languages, sold more than 10m copies, was adapted into a film and is still taught in schools and colleges across the US.

I was 16 years old and in college when I first read *Black Like Me*. I can vividly recall the impact it made on me: as an Asian teenager growing up in the 1980s I felt like a second-class citizen. There wasn't any literature that I had come across that spoke directly to my experience and so I embraced the literature of black America. I read the speeches of <u>Martin Luther King</u>, <u>Richard Wright's Native Son</u> and <u>Ralph Ellison's Invisible Man</u>, but *Black Like Me* struck an especially powerful chord partly because of Griffin's rage at the injustice of racism. In my own case, *Black Like Me* was not prophetic. Does it have any relevance 50 years after it was published?

Today the idea of a white man darkening his skin to speak on behalf of black people might appear patronising, offensive and even a little comical. Griffin felt that by blacking up he had "tampered with the mystery of existence", which sounded profound when I read it at 16, but now seems typical of Griffin's rather portentous prose, which occasionally makes one doubt the credibility of what he is describing. Would the doctor who administered the medication really have told him, on shaking his hand and waving him goodbye, "now you go into oblivion"? Later Griffin notes that when he sits down to write to his wife, he finds he is unable to do so: "The observing self," he recalled, "saw the Negro write 'Darling' to a white woman. The chains of my blackness would not allow me to go on." This, to me, lacks plausibility. Other questions emerge in the rereading: how is it that a 39-year-old white man can pass himself as black simply by darkening his skin and shaving his hair? Did no one notice his Caucasian features and become sceptical of the white man with weirdly dark skin? It is also striking how confidently Griffin seems able to inhabit the black mindset and speak for all black men, within, it seems, only days of starting his journey. Despite these misgivings, Black Like Me remains for me a brutal record of the indignities suffered by blacks in segregated America; it is also a reminder of how, in some respects, things have progressed.

Three months before its publication, <u>Barack Obama</u> was born in Hawaii. It is fascinating to speculate on Griffin's response had he been told, while on his odyssey through the segregated south, that a baby boy born to a Kenyan man would within 50 years be president of the United States. Obama's occupancy of the White House is, one could argue, emphatic proof that the world depicted in *Black Like Me* is history.

Obama's mother was white – but he made an explicit decision, which he describes in his memoir *Dreams From My Father*, to embrace a black identity. This selfconscious immersion into blackness led him to move to Chicago, to become active in the church, to familiarise himself with the canon of black literature and the civil rights movement so that he could claim his presidential hopes represented the fulfilment of the civil rights dream. Obama's case is of course different to Griffin's, but in one sense he, too, was not born black – he became black. The similarities between Obama and Griffin are not, however, the primary reason why Black Like Me still speaks to us from a distance of 50 years; it resonates because its true topic is not race but humanity. Today in the US and elsewhere, Muslims have replaced blacks as the minority who are demonised, stereotyped and dehumanised. "To be a Muslim in America now is to endure slings and arrows against your faith," a recent cover story in Time magazine declared, "not just in the schoolyard and the office but also outside your place of worship and in the public square, where some of the country's most powerful mainstream religious and political leaders unthinkingly (or worse, deliberately) conflate Islam with terrorism and savagery."

Look at the footage of the protests against the inaccurately dubbed "Ground Zero mosque" – the expressions on the faces of the protesters seem eerily familiar. The footage may be in colour, but it brings to mind grainy black and white archive film of protests against integration. The hate stare, described so starkly by Griffin, scarred the faces of these protesters. There is a man with a black father in the White House, but there is also another black man, <a href="Herman Cain">Herman Cain</a>, who is seeking the Republican nomination to become the next president, who has said that any Muslim serving in his administration would be forced to take a loyalty test. "The Negro. The South. These are details," Griffin wrote in his preface. "The real story is the universal story – one of men who destroy the souls of other men. It is the story of the persecuted, the defrauded, the feared and detested." As long as one group persecutes, fears and detests another, *Black Like Me* will, sadly, remain essential reading.

Black Like Me: 50th Anniversary Edition is published by Wings Press (£15.93).

Black Like Me may be read (free) at Archive.org:

https://archive.org/details/blacklikeme1961grif

Race in John Howard Griffin's Black like me may be read (free) at Archive.org:

https://archive.org/details/raceinjohnhoward0000unse/page/n147/mode/2up

## Appendix C Use of Ableist Words and Phrases

# Rethinking language The rising debate around the use of ableist words and phrases

Melanie Earley05:00, Jun 13 2021

https://www.stuff.co.nz/national/125189481/rethinking-language-the-rising-debate-around-the-use-of-ableist-words-and-phrases

Dr Huhana Hickey is organising a protest outside parliament to lobby for more disabled voices in government.

The words 'crazy', 'mental' and 'lazy' may be a standard part of many of our vocabularies, but is it possible the use of certain words and phrases could be causing harm to millions of people? Melanie Earley reports.

In recent years, especially <u>on social media</u>, there has been some debate about "ableist" language, and what words should be avoided in order to not demean people with disabilities or mental health issues.

Jonny Wilkinson, CEO of Tiaho Trust, a disability service in Northland, said the way he saw it was ableist words were used to "taunt" people with disabilities.

<u>The Oxford English Dictionary</u> described ableism as discrimination in favour of ablebodied people, with the example "we were fed up with the ableism of the women's movement".

"We have the more obvious language like the word 'retard' – but there are so many other words that are ingrained into our language, we don't even realise we're saying them," Wilkinson said.



JONNY WILKINSON/SUPPLIED

Jonny Wilkinson, CEO of Tiaho Trust said ableist language "taunted" people with disabilities.

An example of this was the word "lame", Wilkinson said, which people used to describe something boring, when originally it meant unable to move.

"Another example would be describing someone as 'suffering' from a condition. Once when I went into a shop somebody asked me what I suffered from, but I don't suffer.

In some cases, however, people with disabilities chose to "claim back the language", Wilkinson said, including people with disabilities referring to themselves as 'crips'.

Professor of Linguistics at the University of Auckland, Robert Greenberg, who is blind, said phrases, such as "the blind leading the blind", may be offensive to some people, but he personally didn't mind it.



ABIGAIL DOUGHERTY/STUFF

Professor Robert Greenberg is the dean of arts and linguistics at the University of Auckland.

"Personally, phrases involving the word blind don't offend me," Greenberg said, "but there may be other people who are blind out there who are offended by it."

Recently, comedian Michele A'Court posted <u>an apology to Twitter</u>, after a joke she made about anti-vaxxers believing vaccines cause autism on the television show *7 Days* was criticised by a number of people online.

"A number of people have been kind enough to be in touch with me to explain any joke referencing autistic people is harmful, it reinforces negative views, and that many people have been hurt by what I said," A'Court wrote.

The apology was met with a mixed response online – some accepted her apology and were happy to move on, while others said the joke had been in "poor taste" and they were "disappointed" with the comedian, while others believed an apology wasn't necessary at all.

"Anything said on a comedy show should be taken as comedy," one commenter said, "the purpose of comedy is to get a laugh".

"I get it was satire, but it clearly has no place in 2021," another commenter chimed in.



ROBERT KITCHIN/STUFF

Disability advocate Dr Huhana Hickey said everyday language could be incredibly harmful to people with disabilities.

<u>Dr Huhana Hickey</u>, a disability advocate, said language could hold immense power over people, and words could hurt.

"Simple, everyday ableist language can hurt others, and while there's more of an awareness now, people with disabilities are still invisible in society," Hickey said.

<u>The Oxford English Dictionary</u> described ableism as discrimination in favour of ablebodied people, with the example "we were fed up with the ableism of the women's movement".

#### melanie .earley@stuff.co.nz

Ableist language was the "language of the ignorant", Hickey said, and it made her and many others feel as though they weren't valued.

"Society uses language they don't think about, and the labels they have placed on us keep us down.

"They say sticks and stone can break your bones, but many a person has committed suicide over the use of words and language."



Advocates are calling for a rethink of how we use certain words, such as "crazy", "lame", and "blind".

Social media wasn't helping lessen the prominence of ableist language, Hickey said, she described it as having a "toxic" effect.

"On social media people are more confrontational and feel like they can say whatever they like, if I have the energy, I like to inform or critique people on their use of words and phrases rather than being aggressive back.

"The key to people being more sensitive with their language is education. Don't hate the person who doesn't know – educate them."



RYAN ANDERSON/STUFF

Hickey said education was the best way to combat ableist language.

Although language was harmful, it could also be beautiful, Hickey said, and educating others was up to everyone.

Shaun Robinson, CEO of the NZ Mental Health Foundation, said certain language could be very demeaning and hurtful, and could make people feel unsafe to be themselves.

"Some words should not be used lightly – living with a mental illness is isolating enough without people using words like 'crazy' or 'bipolar' in derogatory ways."

Robinson said there was stigma and fear around mental health issues and describing someone as being mental, crazy or schizophrenic, wasn't helping to change this.



CHRIS SKELTON/STUFF

Shaun Robinson is the head of the New Zealand Mental Health Foundation and lives with bipolar disorder.

"I mean, we all slip up at times, I myself sometimes find myself saying 'oh that was crazy', I think it all depends on the situation and intent behind the language.

There had recently been a strong worldwide move to use the term "mental distress" in place of "mental illness", Robinson said, as it was a more inclusive phrase.

"Every person has experienced distress at some point in their lives, and the change can help make it seem more normal."



CHRIS SKELTON/STUFF

The Mental Health Foundation was moving away from certain terminology that could be considered ableist, Robinson said.

"It's about picking your battles," Robinson said, "and also about context. If one of my friends was texting me and said they'd had a crazy day I probably wouldn't pull them up on it for example, unlike if a stranger spoke to me and described someone as being crazy."

ACT Party leader David Seymour, who has <u>been vocal about freedom of speech</u> in the past, believed the policing of language and words that may be considered offensive to some made people feel unable to express their views for fear of backlash.

"You have to walk on eggshells with the language you use, which I do think is worrying. The code of communication has been weaponised.



ROBERT KITCHIN/STUFF

David Seymour recently did a tour tackling free speech across New Zealand.

"I've spoken with market researchers who said it was harder than ever to get people to talk, open up and share their own opinions as they don't want to go against the general narrative."

Seymour believed open discussion made society kinder, and it had become a "trend" to enforce strict ways of communicating and rigid structures had been place on people.

"At the core of it I think we should treat each person with kindness and dignity, but this policing of speech almost reminds me of the Victorian times.

"I don't think telling people they can't do or say something is right."

Seymour noted that most people who used language that could be labelled as ableist weren't using the words to intentionally oppress another person.

The thing Seymour believed people should keep in mind was to treat people the way you wanted to be treated.

Greenberg said eliminating language considered ableist from everyday speech would likely not be possible.



ABIGAIL DOUGHERTY/STUFF

We need to be careful not to take the 'zest' out of language, Greenberg said.

"There are so many expressions which are embedded into our everyday speech that could offend someone, but the way we use these expressions is often metaphoric."

Language was all about emotion, Greenberg said, and the way people spoke could differ greatly from a workplace setting to being at home with friends.

"There are certain words, swear words for example, that we may not use in certain settings, but in others we may say those four-letter words freely.

"It's good to be aware of how the words we use may affect others, but we don't have to stop using that language altogether."

One worry with policing words too closely would be to take the "zest" out of language, Greenberg said.

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- "Language is often spontaneous, and over-thinking every word we use can be a bit over the top.
- "Some of the words which activists have now labelled as ableist are so ingrained into our speech I don't think we can get rid of it."
- "Words can be offensive," Greenberg said, "and next time you use such words maybe think about how it could make others feel.
- "But we don't want to make language sterile when it is so rich."

Wilkinson said if everyone made small changes to their language it could help others feel more safe and included.

"It's just about tweaking our language slightly, like calling someone a wheelchair user rather than wheelchair bound. It's a very nuanced issue."

# **Appendix D** Disabled Cultures

I am not blind

But you can't see I am not deaf But your ears are

A million times more closed Than mine. I am not dumb But you speak nothing

Intelligible. I am not epileptic But you have fits

At the mere thought of

Disability. I am not paralysed But you are more unfeeling Than a stone. I cannot walk But you are more unmoving Than a mountain. I am weak But my willpower is even Stronger

Than your fixed determination To give me degradation And worse treatment

Than baggage.

(Ellen Wilkie, 1989)

I am not blind

But you can't see I am not deaf

But your ears are A million times more closed Than mine.

I am not dumb But you speak nothing Intelligible.

I am not epileptic But you have fits At the mere thought of Disability.

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But you are more unfeeling Than a stone.

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I am weak

But my willpower is even Stronger Than your fixed determination To give me degradation

And worse treatment Than baggage.

(Ellen Wilkie, 1989)

# A brief history of disability in Aotearoa New Zealand

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Compiled by Hilary Stace and Martin Sullivan, October 2020	

https://www.odi.govt.nz/guidance-and-resources/a-brief-history-of-disability-in-aotearoa-new-zealand/

# Appendix E Disability Culture Extracts from Far From the Tree by Andrew Soloman

#### page 23 last paragraph

There is something ironic in prejudice against the disabled and their families, because their plight might befall anybody. Straight men are unlikely to wake up gay one morning, and white children don't become black; but any of us could be disabled in an instant. People with disabilities make up the largest minority in America; they constitute 15 percent of the population, though only 15 percent of those were born with their disability and about a third are over sixty-five. Worldwide, some 550 million people are disabled. The disability-rights scholar Tobin Siebers has written, "The cycle of life runs in actuality from disability to temporary ability back to disability, and that only if you are among the most fortunate."

#### page 23 last paragraph

The difficulties such families face have long been acknowledged by the outside world; only recently have the pleasures become a topic of general conversation. Resilience is the contemporary gloss on what used to be thought of as perseverance. It is both a way to reach larger objectives—functionality and happiness—and an objective in itself, inseparable from what Aaron Antonovsky, progenitor of the study of resilience, calls a "sense of coherence." Parents whose expectations are diverted by children with horizontal identities need resilience to rewrite their future without bitterness. Those children need resilience, too, and ideally parents foster it. Ann S. Masten wrote in American Psychologist in 2001, "The great surprise of resilience research is the ordinariness of the phenomenon." Resilience used to be posited as an extraordinary trait, seen in the Helen Kellers of the world, but cheery recent research suggests that most of us have the potential for it, and that cultivating it is a crucial part of development for everyone

#### page 25 last paragraph

While optimism can propel day-to-day life forward, realism allows parents to regain a feeling of control over what is happening and to come to see their trauma as smaller than it first seemed. The potential pitfalls are wishful thinking, selfblame, escapism, substance abuse, and avoidance; resources might include faith, humor, a strong marriage, and a supportive community, along with financial means, physical health, and higher education. There is no definitive roster of strategies, although words such as transformation and enlightenment occur. Studies are highly contradictory and seem often to reflect researcher bias. Numerous studies, for example, show that divorce is more frequent among parents of children with disabilities, and an equal number show the divorce rate is significantly lower among such parents; further research finds divorce rates consistent with those in the general population. Parents who cope poorly with a disabled child are worn down by the effort in the same way that parents who are coping successfully seem to grow strong, but all of them are both worn down and strengthened. Being part of a group seems consistently to have meaning; the redemptive power of intimacies born from struggle is immense. In our Internet age, when every challenge or disability has a community attached to it, the parents of people with any given challenge can find their horizontal community as well. Although most families do find meaning in their predicament, fewer than one in ten professionals who deal with them believes it. "I was determined not to be around folks who saw us as tragic." one exasperated mother wrote. "Unfortunately, that included my family, most professionals, and just about everyone else I knew." A doctor's or social worker's refusal to recognize such parents' reality because it is happier than anticipated is a kind of betrayal.

#### last paragraph page 26 and page 27

My study is of families who accept their children, and how that relates to those children's self-acceptance—a universal struggle we negotiate partly through the minds of others. In turn, it looks at how the acceptance of the larger society affects both these children and their families. A tolerant society softens parents and facilitates self-esteem, but that tolerance has evolved because individuals with good self-esteem have exposed the flawed nature of prejudice. Our parents are metaphors for ourselves: we struggle for their acceptance as a displaced way of struggling to accept ourselves. The culture is likewise a metaphor for our parents: our quest for high esteem in the larger world is only a sophisticated manifestation of our primal wish for parental love. The triangulation can be dizzying

page 28 first paragraph

In spite of these persisting challenges, the disability rights movement has made tremendous strides. The US Rehabilitation Act of 1973, passed by Congress over President Nixon's veto, prohibited discrimination against people with disabilities in any federally funded program. This was followed by the Americans with Disabilities Act, passed in 1990, and several subsequent acts that appeared to shore it up. In 2009, Vice President Joe Biden opened the Special Olympics by declaring special-needs advocacy a "civil rights movement" and announcing the new post of special assistant to the president for disability policy. The courts, however, have narrowed the scope of laws pertinent to disability, and local governments have often ignored them altogether.

Members of minorities who wish to preserve their self-definition need to define themselves in opposition to the majority. The more

accepting the majority is of them, the more rigorously they need to

do so, because their separate identity collapses if they countenance its integration into the majority world. Multiculturalism rejects the 1950s

vision of a world in which everyone is subsumed by uniform Americanness, and chooses one in which we all inhabit our own treasured particularities. In his classic work Stigma, Erving Goffman argues that

identity is formed when people assert pride in the thing that made them marginal, enabling them to achieve personal authenticity and political credibility. The social historian Susan Burch calls this "the irony of acculturation": society's attempts to assimilate a group often cause that group to become more pronounced in its singularity.

When I was in college in the mid-1980s, it was common practice to speak of the "differently abled" rather than the "disabled." We joked

about the "differently gruntled" and the "differently agreeable." These

days, if you talk about an autistic child, he differs from "typical" children, while a dwarf differs from "average" people. You are never to use

the word normal, and you are certainly never to use the word abnormal.

In the vast literature about disability rights, scholars stress the separation between impairment, the organic consequence of a condition, and

disability, the result of social context. Being unable to move your legs, for example, is an impairment, but being unable to enter the public library is a disability.

An extreme version of the social model of disability is summarized by the British academic Michael Oliver: "Disability has nothing to do

with the body, it is a consequence of social oppression." This is untrue, even specious, but it contains a valid challenge to revise the preva

#### page 29

lent opposite assumption that disability resides entirely in the mind or body of the disabled person. Ability is a tyranny of the majority. If most people could flap their arms and fly, the inability to do so would be a disability. If most people were geniuses, those of moderate intelligence would be disastrously disadvantaged. There is no ontological truth enshrined in what we think of as good health; it is merely a convention, one that has been strikingly inflated in the past century. In 1912, an American who lived until the age of fifty-five had had a good, long life; now, death at fifty-five is considered a tragedy. Because most people can walk, being unable to walk is a disability; so is being unable to hear; and so is being unable to decipher social cues. It's a matter of votes, and the disabled question these majority decisions.

#### pages 31 and 32

Most adults with horizontal identities do not want to be pitied or admired; they simply want to get on with their lives without being stared at. Many dislike Jerry Lewis's use of pathetic children to get funds for genetic research. The NBC news correspondent John Hockenberry, who has a spinal injury, said, "Jerry's kids' are people in wheelchairs on television raising money to find a way to prevent their ever having been born." The anger is pervasive. "Adults responded to my difference by helping me, but some of my schoolmates responded by calling me names," wrote Rod Michalko, who is blind. "Only much later did I realize that helping and name-calling amounted to the same thing." Arlene Mayerson, an expert in disability rights law, contends that benevolence and good intentions have been among disabled people's worst enemies throughout history. The able-bodied can be generous narcissists: they eagerly bestow what they feel good about giving without considering how it will be received.

Conversely, the social model of disability demands that society modify the way business is done to empower people with

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#### disabilities, and

we make such adjustments only when lawmakers accept that life can be

painful for those who live at the margins. Patronizing gestures can be justly scorned, but increased empathy is often a precondition of political acceptance and an engine of reform. Many disabled people say that

the social disapprobation they experience is much more burdensome than the disability from which they suffer, maintaining simultaneously

that they suffer only because society treats them badly, and that they have unique experiences that set them apart from the world—that they are eminently special and in no way different.

#### page 47

This book's conundrum is that most of the families described here have ended up grateful for experiences they would have done anything to avoid.

# **Appendix F** Disability Culture Extracts from: The Deaf Challenge

I know myself only too well and am continuing to discover things about myself, some of which delight and some of which disturb me. This is the natural outcome of personal growth. Although, from time to time, I can see myself behaving in ways which shock or disturb others, I am learning to recognise why this happens and that by behaving in this or any other way, surely I am not so very different from the majority of my fellow human beings? However, I have made a startling observation in recent years. Apparently, I am vastly different from this majority and my behaviour, whatever form it takes, is, in the eyes of that majority, a negative 'symptom' of my difference. If I were then to believe what I see, I would conclude that I am not me, but some kind of construct of other people's perceptions of a small part of me. Thus, I am conscious that I have spent a large part of my life isolating myself from the de-humanising, blinkered vision of the majority out of a sense of self-preservation, a need to understand why these perceptions existed, and a strong conviction in my right to be human.

Arriving at an understanding has not been easy — recognising our own reality and how it merges or conflicts with the reality of others is never easy and takes a great deal of time and patience. Within the confines of the deaf -hearing dichotomy, however, feelings can become very confused from whichever perspective they are viewed. Even my early life was characterised by the growing recognition that the path of self-exploration and the achievement of self-realisation could be steep, rocky and strewn with obstacles and challenges which needed to be cleared or explained before the journey could proceed.

As a deaf child I was objectified as 'impaired' and not 'normal'. This became central to my self-esteem under the wealth of external reinforcements, from the abuse of psychological testing to 'does she take sugar?' attitudes. <sup>1</sup>

1 This refers to the situation where a person is seen to be incapable of communicating directly or making decisions for themselves. Questions are therefore directed at a third party who is expected to answer on behalf of that person, often as if that person were not in the room.

I subsequently retreated into and gained solace from a fantasy world peopled by characters who were more companionable than those who occupied the real world. In this world, it did not matter what I lacked because that could always be imagined and allowed to assume its proper place in the identity that was attempting to shape itself in spite of the wiles of the adult majority. Being deaf could be transformed into something beautiful and colourful, something good. I can remember feeling greatly confused, even angered by the dichotomy between the messages of the verbal and the more subtle communication of bodily language and facial expression, by the depth

of a glance that could warm or freeze. Even in those early days, I suppose I was given to philosophical musings, because I wondered how the doleful eyes of my dog could convey the same depth of expression and the same feelings; and yet there were no words. I looked at flocks of birds in the sky, flying in formation, great shadows sweeping across the fields, perfectly ordered and perfectly harmonised, and the patterns within patterns of trees and oceans, and saw communication; and yet there were no words. I felt the rippling, velvet muscles of horses and sensed the language of excitement at the imminent taste of freedom in the world outside the stable-box; and yet there were no words. But the words, by themselves, conveyed little; they became a cacophony of noise, and feelings became jarred by the distortion. Finally, there were no words for me, only 'a mouthful of air' (W.B.Yeats, quoted in Burgess, 1992) and a jumble of lip patterns which, in their defiance of the laws of nature, could not create order out of chaos. So deficient were the spoken dialogues of the real world that it was not long before the desire to bring to life my inner landscape translated itself into the dance of words before my eyes.

As my isolation continued, I began to put names to vague feelings. The process of learning was given more profundity by the time available for reflection and for searching deeper for understanding by opening myself to the truths of others. Again, perhaps, we feel echoes of the counsellor's trade for, like many counsellors, I read anything and everything to broaden my horizons and I write and re-write my journey through life and my relationships with others. But, for a long time, my reading was another manifestation of my fantasy world, a substitute for the world I had lost. As I searched deeper, I came upon the work of practitioners and theorists as diverse as Carl Rogers, Abraham Maslow, Michel Foucault, Alice Miller, Sheldon Kopp, C.G. Jung, Virginia Satir, Liz Greene and Dorothy Rowe. Their words communicated and continue to communicate to me a penetrating sense of meaning which assists me in understanding what I do and who I am and enables me to go one step deeper in my search for truth. They also granted me words when I

had none, have opened doors when the majority closed them, and have given me life when I might have been condemned to the half-life of a construct who could be re-built and moulded on the whim of the majority.

As I sought my own way of building my self, my 'real' education continued. To stand a chance of furthering myself I was told that I had to be prepared to climb the precipice, suffer the cuts and bruises to my sense of humanity in silence and cope with my broken ears. Only then could I attain the prize awaiting me at the top. I dutifully climbed, feeling hollow inside, and was hurt. When I reached the top, I discovered that the prize was a life in the hearing world, under the guise of a hearing identity — whereupon I suffered an acute attack of vertigo because I realised that I was being offered the stick without the ice-cream 'for my own good' (Miller, 1987a, 1987b). The precipice became a different kind of symbol. It meant that I became my broken ears and that there was nothing in between. The chasm which had opened up between who I thought I was and who I actually was was of such enormity that my roots had become shrouded in the mists of the past. I had, in effect, lost my self. Correspondingly, as the hearing world moved the goalposts further and further away, I lost faith in my ability to achieve and lost touch with both my

own feelings and the feelings of others. It was at this point in my life that I had, in the 1970s, my initial contacts with the counselling community, first as a client and later through an introduction to counselling skills and experiential encounter groups. It was as if I needed to establish a bridge between the client and the counsellor part of myself, as if I wanted to find my own wise counsel because I had been so often betrayed by the counsel of others. I was finally found, and 'held', enabled to feel safe, and empowered to rebuild my life and to find love through counselling. But my story is not yet over, for there are elements of it which remain in a half-light, hidden behind the explicit messages it carries. It is the deeper meaning of my story that constitutes The Deaf Challenge.

It is a predisposition of the hearing world to believe that language is confined to spoken language and therefore that 'hearing' is inseparable from language and communication. Thus, from the counsellor's perspective, it could be said that the possibility of not hearing or of not speaking becomes synonymous with a loss of infinite proportions in experiential, psychological and socio-emotional terms; this runs the risk of being displaced onto clients who harbour the deepest of feelings but may not have the words or the language to 'talk' them through. The prospect of blocked or damaged communication within the counselling relationship can therefore become associated with professional failure. For those that do not know themselves in the counsellor's way, the risk of displacement is even greater.

American psychologist and linguist, Harlan Lane, well known as a chronicler of the lives and history of deaf people, has referred to the fear of losing speech and hearing as 'existential dread' which originates from an 'extrapolative leap' or 'egocentric error' made by hearing society which is based on a stereotypical view of the state of deafness. He says:

To imagine what deafness is like, I imagine my world without sound — a terrifying prospect, and one that conforms quite well with the stereotype we project onto members of the deaf community. I would be isolated, disorientated, uncommunicative, and unreceptive to communication. My ties to other people would be ruptured. I remember my parents censoring me with silence; it was bearable for four hours, and then I implored their forgiveness. I recall the "silent treatment" of offenders in the army. The Tunisian novelist Albert Memmi, author of several sociological studies of oppression, observes in his book on dependency: "The person who refuses to communicate severs the psychological ties that connect him to the other person. In so doing, he isolates the other person and can drive him to despair." A world without sound would be a world without meaning. What could be more fundamental to my sense of myself than my sensory milieu — unless it be my spoken language?'

(Lane, 1992, pp. 10-11)

While deaf people search for a meaningful existence, they are faced with the knowledge that existential dread has eaten its way into the core of the counselling profession and the minds of even the most eminent of psychotherapists:

'Most recently, I have been into something so serious, comprehensive and preoccupying, that I have chosen to discuss it

with all of my patients, in groups and individually. The problem was physical, but had many overwhelming feelings related to it.

About three years ago, I suffered a sudden and profound hearing loss in my left ear. It was diagnosed correctly as irreversible nerve deafness but was mistakenly attributed to an exotic, highly selective virus. Hearing aids were of no use, and after a brief period of panic (lest I lose the hearing in my other ear), I adjusted with counter phobic insistence that other people recognise my limitation; sorry they had to contend with it, but after all I give a good deal, and there was no reason why they couldn't help out by speaking up.'

(Kopp, 1971, pp. 159-60, italics added)

The goal of a common language is a seductive one, for language is the means by which human beings live together and the medium of their cultural and experiential expression. The presence of an 'alien' language strikes fear into the soul of the outsider, because it has no meaning relative to the experience or culture of that outsider. Thus, as Lane says, the prospect of losing the means of living causes deafness to become a hurricane sweeping across the inner landscape and demolishing everything in its path. Whose fear is this and from whence came the hurricane? And why is that fear etched in the inner landscapes of so many deaf people, who, even if they are successful in reaching the top of the contrived precipice, arrive with open wounds and emotional scars which serve as a constant reminder of their deaf selves? Deafness and hearingness are the two ends of a vast and complex continuum which tends

to be regarded as a divided community; but it is the legacy of the hearing majority that the two ends of the continuum came to be perceived as two distinct groups in the first place. They are psychologically, like strength and weakness, but two sides of the same coin, and, in being so, are inseparable. It may be that the emphasis on the positive aspects of being deaf or on 'coping' with deafness is linked to a widespread and very human tendency to shy away from the 'problems' of others to the point of outright dismissal guided by the old philosophy 'laugh and the world laughs with you, weep and you weep alone'. In counselling terms, we need to be careful with the attribution of value; admiration or respect for one side of the coin should not result in the oppression of the other, for all clients deserve the opportunity to feel safe and to grow from the sanctuary of the counsellor's core values and not from the precariousness of the counsellor's deepest fears. Counsellors who remain unaware of these fears are at risk from perceiving their deaf clients "problems' to be the result of an anomaly, with a 'solution' which resides in the belief that accepting a narrow interpretation of the 'norm' will somehow resolve a deaf person's internal struggles. Against such a background, the 'solution' will be incomplete and temporary, and possibly lead to a situation where the client becomes dependent on the counsellor or, at worst, is irreparably damaged by the misconceived values underlying counselling process.

It has long been my belief that, in essence, counselling is 'all about loving' and that counsellors reject 'the pursuit of authority or control over others' in order to 'seek to share power' (Mearns and Thorne, 1988). I find it hard to grapple with the evidence that counsellors, in being human, are not infallible to the abuse of power or to the forces of prevailing attitudes and assumptions about deaf people, though it is not difficult to see how this has happened. Counsellors will have very little information about deaf people, unless they have lived or worked with number of them. They could be forgiven for general assumptions such as all deaf people can learn to speak, all deaf people use sign language, all deaf people feel bad about being deaf, all deaf people want to be hearing again, BSL is the natural or preferred language of all deaf people, because these are examples of general statements which are made time and time again in denial or in ignorance of the diversity of Britain's deaf community. Moreover, these statements say nothing about Black deaf people, deaf women, deaf gays and lesbians, older deaf people, deaf children and so on because the focus is on deafness and not the individual deaf person. But this does not explain away the ample evidence that the existence of deaf people has been widely ignored within the counselling profession, which can be seen in the absence of reference to deaf people in highly respected counselling texts and on most training courses. Existing trends suggest further that the counselling profession runs the risk of taking the same route as other professions in formulating its understanding of deafness. History repeats itself, as deaf people are once more being marginalised to fringe activities and are being prevented from gaining valuable insight into counselling process or contributing to it, because they are being viewed within the context of an 'infirmity' or 'medical' model of disability. 3 4 Within the counselling profession, I find the use of this model, and the assumptions that underpin it, difficult to reconcile, because it seems to work against acceptance and non-judgemental-ism and to deny the role of societal attitudes and assumptions in shaping the individual identity. This is particularly important because this book is necessarily about people, about their inner worlds of feelings, thoughts and intui-tions, about their own experiential landscapes and their relationships to those of other people, and, in particular, about their need to harbour a strong and real sense of themselves. Deaf people, whatever the reasons for their deafness, or their linguistic or cultural affiliations are capable of leading the counsellor into unexplored territories. If influential members of the profession can experience, even temporarily, existential dread, what hope is there for the deaf client who, on seeking help, realises that he or she personifies something of which the counsellor is very afraid? Such a polarisation may well exist within many deaf—hearing counselling relationships, and possibly, as we shall see, within deaf—deaf counselling relationships also. But this polarisation seems to belie the fabric of communication of which we are all a part, despite our different

experiences. Rather than learning how to deal with fear and preju¬dice, or the perceived threat of professional inadequacy by viewing The Deaf Challenge as an opportunity for further growth and understanding, the paro¬chial view of the hearing majority within the counselling profession mitigates against a truly integrated approach to counselling capable of responding to all manifestations of deaf clients' problem situations and contexts, and has worked against access of some deaf people to the therapeutic milieu:

'This propensity to stereotype deaf people as difficult and high-risk candidates for (counselling), as is done with the poor, disadvantaged, disabled, old, and nonverbal populations serves only to thwart their opportunity for emotional growth and psychological enhancement.'

(Sussman, 1988, p.5)

Counsellors may yet be ignorant of the knowledge held by those who work with deaf people. This is that medical and infirmity models of disability have their origins in a history of oppression which has ensured that deaf people are part of a dependency culture who are 'cared for' by the hearing majority. It is this image of deaf people which has been perpetrated by those who, contrary to the counsellor's creed, do not wish to share power nor accept deafness as

- The 'infirmity' or 'medical' model of disability or deafness is based on the assumption that disability or deafness is an illness, and the consequences are ultimately the responsibility of the person who 'suffers from the illness. Such models deny the possibility that a person who is disabled or deaf, as part of the intricate network of society, can be disabled by society which as a whole has come to view deafness or disability in terms of disabling models and stereotypes and therefore contributes to the way in which disability or deafness manifests itself in the individual.
- In the 1993 edition of the Handbook of Counselling in Britain (edited by Dryden, Charles-Edwards and Woolfe), there is one chapter devoted to 'Counselling people with disabilities/chronic illnesses' which states as one of its five principles: 'People with disabilities and handicaps should be offered counselling which is as near "normal" as possible'. It does not mention deaf people.

  a different kind of 'norm'. It can be anticipated that if the counselling profes¬sion were to respond to The Deaf Challenge by remaining true to its core values, and working towards the empowerment of deaf people, it will cause a great deal of trouble for those who use these models as frameworks for their work with deaf people:

When we accept and value our own self we cease to be afraid of other people. We no longer have superiors and inferiors, but only equals with whom we can co-operate and share while we take responsibility for ourselves. We no longer feel deprived and envious, so we can abandon revenge and greed. We have learnt the wisdom of Lao Tsu: "He who knows that enough is enough always have enough." Because we value ourselves, we value others, now and to come, and the planet on which we all live. We reject those who seek to dominate and manipulate us, and who, in elevating greed, revenge and pride to virtues, place our lives and our planet in jeopardy. Obviously, if we all decided to accept and value ourselves, we would cause those who have power over us a great deal of trouble.'

(Dorothy Rowe, in Masson, 1989, pp. 22-23)

I am deaf, and in being deaf I, like many other deaf people, present a challenge to the communicative foundations, the norms and the values of a hearing world. I am also a counsellor, and in being a counsellor, my task in life is often to challenge my clients' negative perceptions of themselves in journeying with them towards personal growth and change. As a deaf person, I have been so demoralised and sickened by what these norms and values mean to deaf people that I have wished I could change the hearing world. I have dreamed of a power-sharing union and of equality, and, in trying to be an agent for change I have wasted energy, sacrificed my sense of self, and lived in a state of constant anger to the point where I was torn to pieces. As a counsellor, and through counselling, I have learnt that the only real change that can be achieved is within ourselves, through the liberation of the unconscious and the acceptance of who we are. Against this, all other change is temporary and transparent. The counsellor's way of self-exploration and self-acceptance has pointed me in the direction of the light from the mire of my darkest hours, but in looking outwards, I have seen that deaf consciousness, in its many different forms, is often prevented from making these discoveries and from learning to value or accept itself. It has become submerged in hearing people's fear of the other side of hearingness, and this has prevented an attraction of opposites which, our learned scholars tell us, is the spice of life and even the bedrock of evolutionary change. Many 'counsellors' working with deaf people have become caricatures of the counsellors I have grown to respect, in their belief that deaf people are 'faulty' and the key to growth therefore lies in conforming to the hearing way. Genuine counsellors do not have the information with which faulty perceptions can be challenged. And so, paradoxically, *The* Deaf Challenge and the counselling challenge, instead of complementing each other, have arrived at this state of

I feel that this embargo is a reflection of the vastly different ways in which counsellors interpret the term 'challenge' and the particular quality of *The Deaf Challenge*. Most practising counsellors acknowledge that helping clients to identify

and challenge self-defeating perspectives on their problem situations is an activity which often occurs in the first stage of any counselling relationship. Self-defeating behaviours are those comfortable but outmoded frames of reference which keep us fettered to patterns of thinking and behaving which may feel safe but which can deny our reality and our creativity. The initial response to challenge and confrontation is often a defensive one, the level of defence being related to the strength of the challenge or confrontation and the degree of safety experienced by the client in their present scenario, and so the skill of challenging carries an aura of risk. The first stage of the counselling relationship can be prolonged if the client is resistant to moving beyond their initial subjective understanding of what is happening to them, and indeed, if the resistance is strong, the client may never move to a position where they can sow the seeds for growth and change, unless the counsellor is prepared and able to take that risk. This is helped by the fact that there is a preponderance of counsellors who are 'first stage specialists' (Egan, 1990).

For the counselling profession, *The Deaf Challenge* is a stern one, because it asks that difficult issues are made explicit and may carry with it a hint that the values of the profession are being undermined. Further, because the challenge comes from a sphere of existence which is largely unknown, it is quite difficult to present it in a way which is not threatening or confrontational, for, in the end it is an expression of deaf people's anger and despair at the harm that has been done to them by the so-called 'helping' professions, with their 'mask of benevolence' (Lane, 1992).

The Deaf Challenge is on two levels. The first is to do with the access of deaf people to counselling and the second is related to the professional contribution that deaf people might make to the development of advanced counselling skills and the understanding of non-verbal communication. It invites the profession to:

move beyond the idea of counselling as a 'talking through' of clients' problem situations

modify stereotyped perceptions and behaviours in respect of deaf people and the concept of deafness modify theoretical and practical approaches to counselling

modify the language of counselling

own their fear of deafness

develop new perceptions of deafness and deaf people which would allow them to face their own challenges from a position of strength

accept their flawed interpretation of critical experiences, behaviours and feelings on the part of deaf people cease evading and distorting deaf people's real issues

identify and understand the consequences of their behaviour towards deaf people abandon resistance to deaf people's uniqueness and recognise its relevance to the counselling profession as a whole.

When faced with the challenge of painful truths, it is sometimes difficult to look beyond the dark storm clouds and see the glimpse of a rosy dawn, because, as counsellors know, few welcome change unconditionally and with open arms, and, as it is part of the counsellor's work to assist clients in finding the inner resources to meet change, it is part of the profession's task to inform itself and to grow. The counselling profession, in common with other helping professions, is slowly beginning to adjust to the reality of our diverse and multi-cultural society, and time is therefore increasingly ripe for introducing new ideas and concepts. But this does not remove the possibility that such ideas and concepts will be challenging, even threatening, because they pose searching questions about counselling process.

#### BOOK AND READER — THE MAKING OF A RELATIONSHIP

My energy finally came to be harboured in using the deaf experience to stimulate the potential for further growth within the counselling community, and to unite deaf people and counsellors in their search for an easier truth and a more valued existence. In this, I hope that *The Deaf Challenge* will appeal to strengths rather than weaknesses. A counselling relationship necessarily begins with both client and counsellor unconsciously, and sometimes consciously addressing their hopes and fears in respect of each other, contained within a confidential, safe environment. The understanding and acceptance of these hopes and fears generates trust, genuineness and empathy, on which all counselling relationships thrive. It follows from this that it is entirely appropriate to begin our journey by developing a deeper understanding of our hopes and fears as counsellors and as deaf people, in order to acknowledge the existence of deaf experience and attempt to understand what this means for deaf people. From my own deaf experience, I am convinced that the hearing way is only one way of being in the world. The 'problem' that deaf people present to the dominance of hearing people is not so much a result of ignorance of this fact, but more to do with the realisation that the deaf way comes from a different 'centre'. I use the term 'centre' here to mean the soul or identity, or the point from which something grows. 5 Deaf people's centre, and the possible source of their unity, at the most fundamental level, comes from their unique experience and their potential to love and express themselves, in different ways, as a response to or through the visual, spatial world. When realised, this potential belies the concept of silence, for the deaf world is not and need not be a silent world made only of fear and prejudice. It can relate to and inform that part of the hearing experience which is implicit and hidden. In our deaf world, we see things and people in ways which hearing

This term has also been used in a slightly different sense by Padden and Humphries (1988) to describe cultural differences between deaf and hearing people, which will be discussed in Chapter 1.

people are often at a loss to understand, and we have given these 'seeing skills' expression in ways which can be transferred. That is, in part, what this book aims to do, but it has presented me with a personal challenge as I float the possibility of relationships. How can I show the experiential divide between deaf and hearing people, and the multiple realities of the deaf community in such a way that empathy can grow? How can I find new options and generate new potential instead of eliminating them? How can I make counselling a more usable, visual experience for deaf people? How can I develop a common language? No matter how clear and straightforward the written words, the concepts explored in this book may have limited meaning for some people because they are presented in a language which can only partially express the deaf experience, and the concepts themselves may be alien to hearing people. I have explored many ways of resolving this problem, and, in the end, I always came back to the words of this book made visual by pictures or images, sometimes serious and sometimes humorous. It is part of my hope that this dual approach will facilitate a joining. Like many deaf people, I am just a small cog in a massive wheel of history and tradition and am searching for truth and justice for the inhabitants of our planet. That I began with my own truth, which, on the surface, may be of little relevance for others, is not something that removes the challenge of the search, nor my belief in the existence of a greater truth and a common humanity, however deeply they are disguised or hidden. I am also, like many counsellors who are still, and perhaps always will be learning from the wisdom of their teachers and their clients, cautious and humble in my expression and driven only to share it in the best way I know how. The 'sailing image' has become an important part of my inner landscape, and I will use it in many different forms throughout this book. In part, I am sure that this is to do with my strong roots in nature, and my love of the symbolism and mystery of natural objects which harbour the clues in my hunt for answers. But it is also because I see the process of counselling as a journey to the island of growth over seas which can be calm, motionless and crystal clear by the light of a guiding moon, or wrecked by tidal waves thrown up by vast storms and the darker side of the moon. As deaf people and counsellors embark from their own communities in their search for the island, they know that they must learn how to sail alongside each other and navigate the waters together. Each boat carries different seeds for learning and for nurture and growth of the other. The deaf world has a beauty, a richness and a vibrancy which is at least equal to that of the hearing world, and certainly complementary to it. Ours is a silence laden with the sound of visual observation, awareness of space, texture, taste, touch and smell. For us, these grant and define our existence in their capacity to inform us of our environment and where we stand in relation to it. Yet our world, which could so easily be a haven of peace, is a world which is constantly under threat from the plague of sound and the flood of denial, and ravaged by the poverty of ignorance. The potential for peace becomes both a Deaf Challenge to the dominance of hearing experience, and a reason for denial as it is twisted by labels such as 'impairment', 'handicap' and experiential 'impoverishment

This book is aimed primarily at those who think they know deaf people better than they know themselves, but it will hopefully be of interest to anyone, deaf or hearing who has contact with deaf people. It is not about clinical settings or patients or about deafness, but about two people in a unique relationship — the counsellor and the deaf client, striving for mutual understanding and deaf empowerment. For the task of this book, and therefore the task of the reader, is a quest for empowerment of the deaf consciousness, and a recognition of the phoenix rising from the ashes, the symbol of The Deaf Challenge and of deaf humanity. In the act of writing this book, I am inviting the reader to experience the essence of that consciousness in the space created by these pages. It is entirely appropriate, in the realms of feeling, that the words of this book should be conveyed in this way. It is a way which is symbolic of both the quality of my silence and of the human need for safety, both yours and mine, when the going gets tough. The words of this book are not easy words to accept or perhaps even to understand, and they may incite the kind of 'trouble' that Dorothy Rowe refers to, but they do not carry a hollow message.

# Appendix G Preparing written materials for neurodiverse people



# Personalized protocols [Making sure organisations meet individual needs]

https://www.asbmb.org/asbmb-today/careers/060119/personalized-protocols [This article was written in USA and refers to ADAct. Some of the concepts in ADAct have been implemented into NZ law, but there are still many gaps remaining in NZ legislation.]

Teresa Evans of the University of Texas Health Science Center at San Antonio and Nathan Vanderford of the University of Kentucky, published a study in the journal Nature Biotechnology last year about mental health among graduate students. The results, Evans said, have "catalyzed an ongoing discussion" about what can be done to improve graduate students' well-being. When Shauna Otto, a Ph.D. candidate at Oregon State University, is working through a bipolar episode and finds herself unable to reach out to others in her lab, her contact at the university's Disability Access Services acts as a buffer, relaying messages between Otto and her primary investigator until she's well enough to re-enter the lab.

Both Agnes' presence and Otto's mediator are considered reasonable accommodations under Title I of the Americans with Disabilities Act; they allow individuals with disabilities to do their work to the same extent as people without disabilities. Rather than specifying which medical conditions constitute disability, the ADA considers a person to have a disability if they have a mental or physical impairment that substantially limits one or more major life activities.

The protections of the ADA and the right to request and receive accommodations extend to students at the primary, secondary and postsecondary levels for a gamut of visible and unseen disabilities, which includes the mental illnesses that a number of recent studies have found graduate students are more likely to have than the general population.

While accommodations can be clear-cut in an undergraduate setting — additional time for tests, an assignee to help with taking notes or even a student helper to lend an additional set of hands in

a <u>chemistry laboratory</u> — the informal nature of research laboratories may leave graduate students and postdoctoral fellows feeling uneasy about disclosing their conditions to their PIs and requesting the accommodations they need.

While anecdotes suggesting a mental health crisis among graduate students had been circulating for years, a number of recent papers helped bring greater attention to the scale of the problem.

The following pages show the version of the Conference Programme intended for most people.





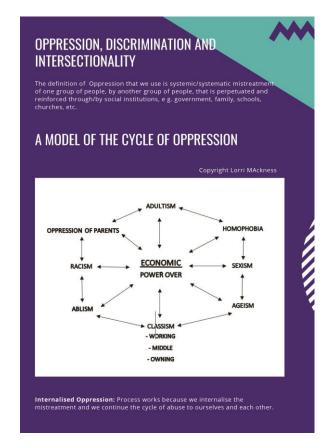




















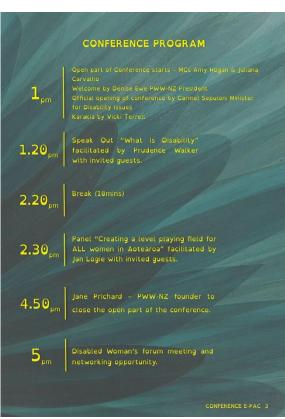


#### Neurodiverse Version of Conference Programme

This version was produced by Tamara and Kundra. It uses fonts that are sans serif. These are easier to read. It also uses text in yellow, for ???? reason.

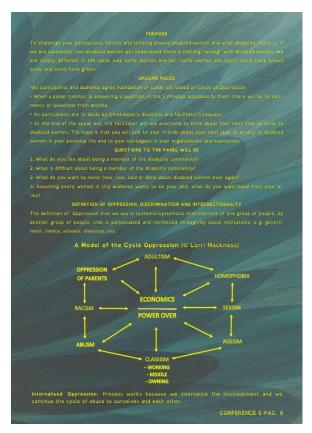












































#### ROSIE PATERSON-LIMA PWW-NZ board member

Rosie has been on the board of PWWNZ for 5 years, and loves working with the members who are engaged across many networks and intersections of our communities in Aotearoa NZ. She is pākehā/tauiwi and raised in Ōtepoti-Dunedin, currently living in Tāmakimakaurau-Auckland where she works in the aid and development not-for-profit sector as a programmes

She is married to a migrant, has a transnational family, identifies feminist, engaged in the faith community, and is passionate about gender justice both here in Aotearoa NZ and also with her work supporting grassroots organisations across SE Asia and South Western Pacific. Inclusion, access, dignity, equality and meaningful participation are core values in her advocacy and work - and she is proud to be an ally amongst communities, friends and family who face challenges when these values are not supported in everyday life and experiences.

#### RHONDA COMMINS

Rhonda is a campaigner for a New Zealand Accessibility Act She is also a member of Blind Citizens New Zealand and NZ View(Vision Impaired Empowering Women). She is a part of Disabled Womens Forum and PWWNZ. Having a degenerative eye condition, she has more than 35 years of lived experience of barriers to inclusion and lives in Auckland.





#### THANK YOU TO ALL THE WONDERFUL PEOPLE BEHIND THE SCENES

What help we have had from an amazing array of people; we do not see them doing their incredible work to make this conference the best it can be. They work behind the scenes, quietly achieving and at the same time this enables us to achieve. They are integral to our success in making this conference come into being.

CONFERENCE E-PAC 11

## **Appendix H Resource Use**

PWW allocated a total budget of \$1500 for the Conference

NZSL interpreters cost about \$1600 and this was generously paid by Drake Medox, courtesy of Gay Barton

Juliana Cavalho's services were offered to a maximum of 8 hours per week by Drake Medox,, courtesy of Gay

Barton

Volunteers provided about 1500 hours of planning and materials preparation time.

PWW provided access to their ZOOM Conferencing account, worth ?????

## Appendix I Disability as seen by NZ Public

Epidemiology Disability is not as rare as most young and able people perceive.

We are born weak and vulnerable, at best.

As we age, we all will personally suffer more and more serious disabilities.

Public Understanding of the Impacts of Disability

Our personal experience of suffering disability mainly comes into play at older middle age. But at a younger age we will first encounter disability in family and friends, if we even notice it. When the possibility of vulnerability or weakness is remote, we can easily fail to appreciate and understand it.

This is where understanding of disability typically starts in the wider public. Initially this may be quite a fearful learning process. As experience accumulates, fear subsides, to leave a more pragmatic, realistic and supportive understanding. This knowledge helps us, if or when we should later fall victim to disability.

Initially people learn more about the physical and visible issues of disability. Over time, this knowledge and understanding may become deeper about the affective aspects of disability. These issues range all the way from loss of access and ability to participate socially, to loss of freedom and privacy, to likely damage to intimate relationships. Different disabled people vary in their ability to manage and handle these affective issues.

Support for People With Disability

Different levels of financial resources make a huge difference in the impact of these disabilities. In some cases, people faced with these realities in their own life, may choose rational suicide, in preference to being in this situation. If the disabled person already has wealth, they have more options open to them and access to pay for supports. In the majority of cases, they and possibly their wider family will be plunged into severe poverty and poor access to supports.

In general, young people are better now than in the past and will often provide significant material help when they see a person with a visible disability, or when a disability becomes visible. Through the last forty years, this improvement has been dramatic.

Although most disabilities impact only a small fraction of the population, put together about 70% of the population have one or more significant disabilities. The idea of making one product, one size fits all, just doesn't work, least of all for clothes.

Public Understanding of the Realities of Life With a Disability

A lady suffering from Parkinson's Disease had a sudden attack of motor dyskinesia. A middle aged woman, who obviously lacked knowledge about Parkinson's Disease, commented "drunk at this time of day" and offered no help. Within a few minutes a young passer by, with a little medical knowledge, offered help to get her home. Although the first lady offered no help, she cruelly humiliated the lady with Parkinson's Disease.

A lady waiting in line at Accident and Emergency overheard a young man being berated by an older nurse. Why are you attempting suicide and wasting our time? Can't you see that we have other patients here with serious medical conditions.? The lady listening said nothing. Although she was a nurse, she did nothing to intervene. She knew that this invalidating treatment would only encourage the young man to be more careful to make sure that his next suicide was successful. This nurse was waiting with her lesbian partner and

did not want to attract attention to themselves, in case it impacted negatively on her partner receiving appropriate treatment. Later she thought it through again and regretted remaining silent.

However, the public's understanding of the affective aspects of disability is generally poor. In some cases, there may be victim blaming and the person may be left without help eg deafness, or mental health issues, or autism or ADHD. These lack of understandings may occur in the general public and also among medical professionals. This often leads invisibly disabled people being even more reluctant to ask for help, from either doctors or from the public.

It might be thought that disabled people would have a much better understanding of the difficulties faced by other disabled people.

This is generally true for the affective problems eg the impacts of stigma or of existing stealth or not disclosing a disability. But there is also a large lack of understanding by many disabled people, of the impacts of other people's disabilities, especially the physical impacts and the details of affective impacts due to unfamiliar disabilities. These lacks of understanding often lead to disputes and arguments between different disabled people. It may be surprising to an able person, the difficulties that other disabled people may face. in understanding. There are so many details in all of these issues.

#### **Difficulties With Service Provision**

It is important to note that many people have multiple forms of vulnerability or disability at the same time. In many cases only one form of disability is addressed in public service provision and people with multiple issues are often seriously disadvantaged.

The service provision workers are also a seriously marginalised group within our society, so that conflicts of interest are often difficult to resolve. These issues make it much harder to protect vulnerable people.

Invisible disabilities put the person in the situation of having to choose whether to disclose their disability, in the hope of receiving help, but at the risk of only receiving stigma and disadvantage. This choice is far more cruel than most able people realise and understand.

Challenges for Providing Effective Protection for Disabled People

Although the Health & Disability Commissioner is well aware of the concepts of vulnerability and disability and tries to offer complaint services that are sensitive and appropriate to these needs, most service providers are narrowly funded with no concern for intersectional issues.

Government budget announcements talk about increases in financial allocations to support services, but fail to mention where funding has been cut. This leads to an extremely untrue perception in the eyes of most members of the public about what any changes actually mean.

In the discussion below, the groups are listed in approximately largest number, to smallest number. The order is not really important, as each person should be cared for appropriately to their needs.

This discussion is primarily about physical and mental health. Financial poverty is also a significant contributor to very low standards of well-being, as people with these issues are frequently poorly placed in the working force or completely unable to work. These problems are usually not short term. In many cases these conditions will persist until end of life.

These issues are described in the report:

2007 Household Incomes in New Zealand Trends in Indicators of Inequality and Hardship 1982 to 2004

Since that report was released, there has been some increase in funding for complaint services and for remedial actions for able complainants. But negligible improvement in remedial actions for at risk or disabled citizens. Poverty has generally become a more severe problem for disabled people and their wider families. In many cases, the increased impacts of income poverty and increased housing costs, has eaten up all the targeted increases in supports.

#### 2020 Health & Disability Commissioner annual report

This report discusses many marginalised groups at greater risk, Women, Elderly, Disabled mental health, Disabled physical, Neglected or abused children. Sexually abused women. Sexually abused men, etc, from the Commissioner's viewpoint. But there is no checking back with his service users, whether they are obtaining effective protection, after the Commissioner has heard their complaints.

DHB funded Service provider organisations are funded on an assumption that they will never hear any complaints about their service or have to fund any remedial actions. This creates a conflict of interest, where service providers are very unwilling to deal with any complaints made, let alone take successful remedial actions, as it takes away their profits. Even if a complaint is heard satisfactorily, it is unlikely that the complainant will receive a successful remedial action. This problem persists, past, present today and future. Although non-disable people have access to funding for protective services, disabled people do not have access to effective and working protections.

## Appendix J Leave No-one Behind - or Why They Won't Listen

These words sound straightforward and simple and ethically beyond question. Take care of widows, the poor and the insane.

These words have been beyond question for more than 4 thousand years, though with more gaps in time than solid observance.

But the Devil is in the detail. The saying "Leave No-one Behind" is surprisingly subtle and complex to apply in our diverse, real world. It has been used as a cry to "End Extreme Poverty". This is a straightforward and simple objective, surely the values involved are beyond dispute?

# It all comes back to open, careful, respectful listening and then acting sensitively on that.

In our own mind, we must not create other people as "other".

It is said that - values are behind the eyes? This is a challenge to how open we can be.

The UN proposes the Multidimensional Poverty Index as a set of values for comparing different people's comparative needs, on a fair basis.

#### **Leave No-one Behind**

This is an expression that those with power or fitness should give every possible support and protection to the weak and vulnerable. **To give care and protection is to dispel fear**.

The saying does not clearly specify whose values should be used to judge?

If the people relating are of one culture, likely there is no problem? But given all of the various aspects of culture, religion, language, ethnicity, sex, gender, colour - the idea of monoculture doesn't really exist in our real world. We do have to face that even in a group of people who look the same, there will be quite a wide divergence of values. If we want a society in which everyone participates on an equal basis, we have to listen to each person's values. If we want to support marginalised or vulnerable people, this is essential to being successful at offering support.

## Respectful listening can only be based on respect for the other person's values.

The saying "Leave No-one Behind" is an old war cry of the US Military Services.

The U.S. military has made a sacred commitment to leave no one behind on the battlefield. This ethos is even embedded in the Airman's Creed ("I will never leave an airman behind") and the Soldier's Creed ("I will never leave a fallen comrade"). If a downed pilot isn't rescued within an hour, their chance of survival drops to about 50-50 and plummets rapidly. This commitment is clear, but at times may be impossible to attain.

2<sup>nd</sup> time – tank crew hear incoming missile alarm, sudden extreme change in power balance. They are out on the street and at risk even from small arms fire.

In advocating for human rights for people, we will often end up comparing apples with oranges. Is it better to be deaf or to be blind?

To apply a different standard to different people would be hypocrisy. But how to we apply the same standard to different situations?

2<sup>nd</sup> time around truck of soldiers takes off suddenly, leaving one man behind, running in vain to catch up.... Again this is a sudden change in power.

"Swapping chairs" is a technique often used in counselling, to help a person to think through the other person's situation and perhaps values too. In these scratchings, I will invite you to feel through "other" people's points of view. I hope that you can gain understanding, so that people different to yourself are not so often reduced to "other". It is an invitation to walk a while, in their shoes or wheelchair. The pain is worth it.

#### **Equality of Opportunity**

It is said that the humanity of a society may be judged from how it cares for its most vulnerable or marginalised members.

Image of scales of justice

The problem for marginalised or disenfranchised people is not so much to "access" justice, but just to be heard at all. This may sound like a trivial problem, if you don't have experience of being not listened to, because you are "other". Getting in the door of a courtroom is relatively straightforward, but to be listened to with equal standing is the problem that usually determines the outcome.

There are none so blind, as will not see.

Jeremiah 5:21 Hear now this, O foolish people, and without understanding; which have eyes, and see not; which have ears, and hear not.

Admiral Horatio Nelson turned a blind eye to his telescope, to avoid seeing the flags ordering him to give up. Nice story. But going through the motions of being listened to in court, when you suspect that you are not being listened to, is an experience of injustice.

A feeling that the other person is "other" ie from an inferior or persecuted group, usually prevents their words from being heard and understood. Paying lip-service to listening, but not trying to understand what is being said – is not **respectful** listening. Swapping chairs does help to put us into the other person's shoes. We may be asked to speak, as if we were them......

The fact that these issues were not being properly handled, led to the Geneva Convention on War.

Conventionally, the victor gets to write history and the story of the marginalised or vulnerable remains untold. And that is how we "educate" our children. This is failing to "swap chairs".

#### **Altruistic Form of The Golden Rule**

It is common to talk about The Golden Rule as simply "Do unto others, as you would have them do unto you".

Easy to say but too often it doesn't result in the quality of outcome that we should be aiming for.

This simple form assumes that the other person wants to be treated as I want to be treated. This might be true in a simple monocultural world, but it is lazy and unsuccessful in the real world that we live in. This is has been known and recorded since 2400 BCE and the solution too.

Even between women and men supposedly of one culture, the monocultural Golden Rule often falls to pieces. We should aim higher, for a better world.

When we wish to protect a person's human rights or create reconciliation between groups of people, we need to look clearly at each person's values and how well they were respected. This is open to differing viewpoints and varying willingness to see another person's viewpoint.

"Do unto others, as you would have them do unto you" essentially makes an assumption that both people have the same values. Especially in situations of dispute, this will usually not be the case. In simpler situations, a legal set of values may be applied equally to both parties, but often the subtleties of human life will be outside of these standardised legal values.

To make our society more supportive, we need to listen in a culturally sensitive manner. To give care and protection is to dispel fear. Can we "swap chairs"?

"Treat others with the respect, that you hope they will treat you" is an improvement, but it is open to a wide range of understandings. The biggest issue is how we behave, when we have limited knowledge about the other person's culture. Even within an apparently mono-cultural group, when we remember that there are differences of attitude and experience, relating to religion, ethnicity, sex, gender, capabilities and enjoyments.

By directly facing these issues, we are better placed to **treat the other person with respect that they will appreciate**.

## **Privilege and Fragility**

A very convenient barrier to being willing to understand another person's values, is seeing them as "other", different and inferior. Then their values don't "need" to be respected, compared to my own.

Another barrier to listening to the other person's values, is not knowing enough to be able to pick up what they are saying. Not speaking the same language is the extreme example, but simply being of different cultures is a more subtle example. Why don't they simply live by my culture is not listening openly.

For these reasons, it is very easy to get bogged down in non-productive arguments.

Traditionally history was written by the victor. The complaints of the vanquished were slowly forgotten as time passed and mainly not addressed at all. When long periods of time have passed, it becomes more and more difficult to sensibly provide redress.

Our law says that theft does not transfer legal ownership, yet we turn a blind eye to historic claims where redress was refused at the time. This is obviously hypocrisy, but the powerful majority are able to get away with this. The grievance is left smouldering. Just get over it, that was in the past! They are still benefiting and don't want any changes.

This is very convenient and advantageous for the powerful. But that is no excuse for simply forgetting about the grievance and killing the people making these claims. As time goes by, such grievances may become stronger. If there is a major change in power structures, then these grievances may come to the fore and result in a new set of killings of the previously powerful. The Balkans have had at least 2500 years of such power changes and killings, or genocides, as various invading powers swept through their country and turned the power structure of their society on its head. This has built up intense grievances and left the society a powder keg for internal killings, abuse and genocide.

Looking at the long term consequences, it is worth addressing these types of wrongs. In many cases, the people benefiting will only take part in reconciliation negotiations if forced by circumstances or some legal authority.

The power structure of our society is not a simple top down hierarchy. In differing situations the power structures may play out very differently and we must be sensitive and take this into account in advocacy or ally-ship work.

Men may have privilege for better wages, but when it comes to issues around military conscriptions they are vulnerable and weak. If sick or dying or very young, again they may be weak or vulnerable.

Parties may refuse to acknowledge their contribution to a problem, or the ways in which they took benefit from a situation.

Fragility is the refusal of the advantaged party to even discuss these issues on an equitable basis. It is their refusal to walk even a small distance in the other party's shoes. When this refusal is problematic, then they refuse to listen to the other party – "other". In these intractable situations, they may be willing to listen to an ally, that is a person they are willing to listen to and respect as a person – the opposite of "other".

Resolving disputes takes lots of patient listening. It may need to put protagonists into swapped seat situations, to pressure them to understand each other's viewpoints, situations and values.

Another example of fragility was the general refusal of counsellors in NZ before 1990 to accept that women could perpetrate sexual crimes against children. If boys ever opened up to counsellors, they were often abused by the counsellors as being liars. Police treated such boys similarly, of you were so lucky!! This dynamic can be seen as women counsellors refusing to accept that women could do such things to children.

In the time since, it has become clear that those boys were telling the truth. Nowadays counsellors do listen appropriately to boys complaining about sexual abuse by women.

Another example of Female Privilege is women not being subject to compulsory military conscription.

When men refuse to acknowledge male privilege and how they have taken advantage, they are acting with Male Fragility.

Fragility is the blunt refusal to walk in the other person's shoes, or to swap seats for a short time.

## Being Vulnerable or Weak

We are all born small, weak and vulnerable. We will be completely dependent on our parents for several years, as we grow in capability and strength. To give care and protection is to dispel fear.

Most of us will die vulnerable and weak.

If we are fortunate, we may be strong and powerful for a time in our life. Even then, in a moment we may become weak and vulnerable again.

As children, some will have suffered sexual abuse or physical neglect or emotional neglect. Some of that abuse may have been by our own parents.

Jesus simply implored us to look after the weak or vulnerable. He didn't discuss blaming victims for their plight, certainly not judging them critically for the situation that they find themselves in.

As a society we have limited resources for helping. To help to the best extent, we do have to judge the situations so that help may be given for the best outcomes. These judgements need to be made, so that our help is given out equitably, not equally or the like.

This will involve values – whose values?

Traditionally, there were lists of what help was given for what situation, very simplified compared to the range of human situations that we come across. In many cases, multiple problems were helped only

according to the single worst problem. Yet is was clear that multiple problems were much more serious than the help being given. At times, the inequity becomes obviously gross and inequitable.

We are trying to compare apples with oranges and there is often no clear answer. As well as the actual weaknesses, different people 's values result that inappropriate help was being given. The decider's values were driving the decisions made, not sensitivity to the recipient's values. This is another example of the difference between the multicultural form of the Golden Rule and the monocultural form.

To make these decisions equitably, we need to be able to walk a distance in their shoes, or wheelchair. We need to see the world, as they see it.

Even if we only advocate or support, we still have to make decisions about who we will give our time or resources to.

Even this short term identifying may be scary or painful. Can we do it at all? Can we go a short distance in their world? Swapping seats may help us to understand, but even then it is just for a short time, with a good escape route. It isn't really the same at all.

We need to go further than waving our hands in the air and making generalisations about vulnerability and weakness. We need to make allocation decisions in individual cases, with claimants yelling in our ear.

How do we handle individual cases fairly?

If we cannot see the disability, it may be very easy to fail to understand it at all, let alone to be able to weigh it appropriately.

If society discriminates against these people, they may be under extreme pressure to not show their disability. Even if we can gain their trust, they will be so inexperienced at being open about the disability, that it is very hard for them to communicate clearly and openly to us. It is very difficult for us to gain appropriate understanding, to be able to advocate for them or support them. We may lack the language to describe such a situation, to communicate to others what is the problem.

Worse still, if we simply refuse to believe them at all. ???

If we as observer are blinded by our own superiority, then we have discounted them as "other". We have built a barrier so that we cannot listen to them, but we may be unaware of this barrier. It is hard to climb over a barrier that we cannot acknowledge, even if we built it ourselves!!!

There are none so blind, as will not see.

Jeremiah 5:21 Hear now this, O foolish people, and without understanding; which have eyes, and see not; which have ears, and hear not.

We can only listen openly if we are able to give human respect – the opposite of discounting as "other". Only if we can respect all faces of their culture. These faces include language, religion, skin colour, tastes, gender, sex....

It is difficult to respect what we don't understand, or don't even know exists. We have to climb over our assumptions, tastes and massive lack of knowledge.

Vandals destroy things that they don't understand the value of. It is very easy to be a social vandal, it takes much care to not be a vandal. It takes humility to listen openly over the top of our own feelings of superiority.

If we are scared to listen to another person's reality, then we have the largest barrier of all to climb over.

If listening will open us up to uncomfortable personal realities, then we have a huge barrier to work with. If listening would expose the privileged advantages we have enjoyed, it will be very uncomfortable to listen to stories from someone who suffered from lack of those privileges. Even worse if it exposes unethical actions we have taken eg stealing from others in some way. We may be extremely reluctant to listen to such stories. This is fragility. It may be white fragility, if the issue is racial prejudice. It may be able fragility, if the issue to able prejudice.

If we dismiss the speaker as "other" in some way, we will never allow ourselves to hear what they are saying.

The only way that the person speaking has a chance to be heard, is by speaking through a respected advocate or ally, who is not seen as "other", by the fragile, privileged person.

A wise person can learn from a fool, but a fool cannot learn from a wise person!

If listening to a person would involve empathising through their pain, we may not be willing to face their pain. We have a free choice, they don't. "Swapping chairs" is not easy.....

It does take quite a lot of personal strength to listen to painful stories. To listen carefully enough, to be able to compare such stories, to make appropriate decisions. Why choose to feel such pain?

It is only through listening carefully, that we can hope to make appropriate decisions.

It is only through appreciating the cultures around us, that we can act appropriately for vulnerable people.

I have discussed emotions of pain and fear. Emotions may be very strong motivators to action. But to act appropriately, we must restrain ourselves and act when we are confident that we understand and we can make a safe and constructive decision?

We need to pause before we pull the trigger. Maybe we need to cool off our own emotions and reactions. Do we know the whole story? Do we need to gather more information or check with someone else? Are there other solutions that we haven't considered? Are we self-regulating?

We can change the world more by careful and slow actions, than by rushing in and acting loudly or dangerously.

Fools rush in (where angels fear to tread).

### **Religious Reversion to Using Fear for Control**

When we look back through history at all of the times that philosophers and religious leaders have proposed the altruistic form of the Golden Rule, most of the leaders that have followed on have reverted to the simplistic form of the Golden Rule, the non-altruistic form.

Some religions have carefully maintained the altruistic form, notably Zoroastrianism 2000 BCE, Judaism (prior to the State of Israel), Druze, Ahmadiyya Islam, Society of Friends (Quakers), Unitarian Church, Bahá' and Buddhists.

These churches are notable for their devotion to peace, justice, caring for the weak and vulnerable and for respecting other religions and not aggressively proselytizing.

Why have follow-on religious leaders and dictators reverted to the non-altruistic form of the Golden Rule? It is because they want to have Ruler's Prerogative and to rule using fear. To give care and protection is to dispel fear.

In choosing ruler's prerogative to come before human rights for everyone, they protect their own non-accountability, power and privilege, at the price of sacrificing altruism and respecting others.

Fear unfortunately is a powerful emotion, which inhibits our own agency and decision-making capability.

#### 1 Corinthians 13 1

Love is patient, love is kind. It does not envy, it does not boast, it is not proud. It is not rude, it is not self-seeking, it is not easily angered, it keeps no record of wrongs. Love does not delight in evil but rejoices with the truth.

## **Changes in the Dominant Group in Society**

Most of us have only lived under one dominant group in our society. Such changes usually only occur a small number of times in anyone's lifetime. In the Balkans, such changes have occurred about 50??? Times in 2500 years of recorded history. The new dominant group had little respect for the previously dominant group.

These sudden changes of societal power were accompanied by settling of old scores, tortures and genocides. Frequently there was little warning of what was coming. Over this long period of time, unsettled scores turned into intercultural hatred, that festered and could burst into flame with no warning. 1990s wars

In the last 100 years we have had 2 world wars and many skirmishes that affected much smaller areas.

Tank crew escaping from tank when it is about to be hit by a missile.... They went from powerful to dead in half a second.

By contrast Alexander the Great around 300 BCE chose to respect his subjugated people's religions and didn't force religious conversions. As long as they didn't fight back and paid his taxes, he was happy and could do what he wanted with minimal interference.

He didn't really do it out of love or respect, more just that this tolerance made societies easier to control. Ruler's Prerogative still came first, he still had the first choice of the boys, his military needs came first. The respect he gave, gave him fewer rebellions that needed to be put down, his empire ran more smoothly.

After the Greek Empire had collapsed and as the Roman Empire was collapsing hundreds of years later, greek ethnic citizens were slaughtered in outlying areas, as a consequence of grievance by then 300 years old. The Greek Genocide in Turkey ?? other places lost several million lives, though the grievances were 3 centuries old.

Sudden changes in power structure may unleash much cruelty, if old grievances have not been reconciled. The sudden power changes put people into swapped seats and their behaviour changed in an instant. After death, there isn't much reconciliation or learning.

## Genocide in the Breakup of Yugoslavia

A harsh example of fragility was the publicly displayed in the breakup of Yugoslavia in the early 1990s. Tito had ruled with an iron fist as a dictator. Although he held the different ethnicities together and achieved cooperation and successful social and economic development, they had not reconciled the impacts of two and a half millennia of alternate conquering by neighbouring civilisations. These cruel conquests had built up an accumulation of hatred and distrust between the different ethnicities. Although under Tito, these rarely boiled over into killings, the fuel was still there and smouldering. On Tito's death, the Orthodox christian Serbs effectively took over and using their majority threatened the minority groups. They had control of the Yugoslav Army, its guns and ammunition.

They decided to murder the Moslems and Croatians in the area and launched rape and murder campaigns. Centuries of unresolved hatred and abuse, burst into cruel action.

There were several wars, mostly bare hands against military rifles and rapists. After the wars had stopped, actions were investigated by EU war crimes investigators. The EU tried to hand over the prosecutions to the successor governments, to prosecute the war criminals living within their territories. This handover was unsuccessful, in that those governments, in particular the Government of Serbia followed through with the prosecutions so slowly, that most cases became un-prosecutable due to the deaths of witnesses by old age. The Serbian Government effectively refused to prosecute, even though they had accepted this responsibility under the articles of accession to the EU. This failure was foreseeable, given that the Serbian Government leaders had very close links to the war criminals.

Some of the war crimes trials were carried out in The Hague, of the most serious war criminals. At these trials, none pleaded guilty when provided with copies of evidence to be presented in the trial (discovery). As the trials proceeded, some of the lower level war criminals did change their plea to guilty. They were able to see, from the viewpoint of time passing, that their actions were criminal, abusive and that the emotional encouragements at the time were not justified when looked at more slowly. They, as young men, had been swept along in the emotions and hate of the moment. They accepted their sentences and apologised to their victims.

The remaining war criminals went on to the completion of their trials and all were found guilty of some or all of their charges. They often abused their victims at the end of the trial and still maintained that their actions were justifiable. They were unable to see their victims as people with human rights. They refused to attempt to reconcile in any way and they totally refused to see their victims point of view.

The younger men who could now see the gravity of their crimes, did at least take what small actions they could to apologise and reconcile for their deeds. They said that they now regretted that they had done those actions. With time to reconsider and better opportunity to understand their victims, they now understood why their earlier decisions were unacceptable.

## Speaking when you have no direct power

Lady giving occupying Russian soldier sunflower seeds. Put these in your pocket, when you die these will grow! She has no power at all, he has a gun and can use it with no accountability.

He doesn't want to listen. He orders her to move on and stop hassling him, but to no effect. He does everything possible to not listen, but to no effect. She is speaking truth and affect, to his short term power.

She is speaking a language that he cannot ignore, of his death, the language of the greatest fear to a soldier, even with a gun. The great personal risk that she is taking only adds poignancy to what she is saying. The soldier knows that she is speaking the truth in every sense. She does not have immediate power, but she has called in power over the soldier, that he is fairly powerless to control. The only power she has, is the obvious fact that at any moment he might die. The contrast of plant life, that goes on with beauty contrasts with the soldier's vulnerability.

Video of captured Russian soldier surrounded by civilian women. Tell me your mother's phone number...The young soldier had no agency in the first place, he was conscripted. He certainly has very little agency as a PoW and a very uncertain future.

As we watch these videos, can we "swap chairs" with each of the protagonists?

Video of older woman civilian abusing occupying Russian soldiers at a protest. Who invited you here? If you are uninvited, you should go home !!!

She is brave, foolhardy even. She knows the risks of being shot or raped. She has seen dead bodies littering the streets and probably seen cold blooded shootings happen. She has the power of truth and her words evoke guilt in the soldiers, even though they don't want to listen to her words. They know that if positions were swapped around, they would feel just the same. Her words cut through the thickest of skins. They cannot help but to hear her, unless they are totally emotionally dead.

Without a possibility of a sudden change in power positions, or support from an ally, the marginalised person has very little opportunity to be heard.

## **Marginalisation and Privilege**

If we add up all of the forms of vulnerability or weakness, it adds up to roughly 70% of all citizens. Why then are so many people so powerless?

Said the other way around, how can a small minority exercise so much power and not-listening?

From time immemorial rulers have used divide and conquer. Royal Prerogative has always come before human rights of everyday people. Rulers have been ruthless to protect their power.

With vulnerable and marginalised people, they are usually not much capable or unwilling to support each other. Thus they leave themselves even more vulnerable. We find it hard to work together.

## **Protecting Human Rights**

In general, it human rights are the right to healthy development as a human being, without undue interference from other people and in so far as it respects other people's freedoms, right to healthy development and protection.

The sharpest tests of the quality of human rights protection, are:

How well the most marginalised members of society are cared for, treated and protected?

Which receives priority, ruler's prerogative or human rights protections of citizens?

We will see that human rights protections have been given to the most powerful and privileged first. Other groups have received human rights protections in the order of those who least needed protection first. In the USA, women received human rights protections after black men and the legal arguments used were leveraged off black men's human rights protections and that women should have no less human rights protections than black men. Even more poignant, is that those protections supposedly enjoyed by black men were more illusory than real, but that was enough to eventually lead to women receiving human rights protections. (Now we have the situation where the compliment could be revered, black men could validly argue that they should have no less working human rights protections, than women !!! But that hasn't happened yet.)

How well have human rights been protected throughout history.

The Code of Hamurabi 1750 BCE is one of the earliest legal codes that we have access to today.

But such even-handed justice was not always the case. The punishments vary significantly in relation to the status of the criminal and the victim. If a physician accidentally kills a free man, for instance, the doctor's hands will be cut off. If a physician kills a slave, however, they need only replace the slave. Similarly, if a free-born man strikes someone of equal rank, he must pay a penalty in gold. But if a slave strikes a free-born man, the slave's ear must be cut off.

We also see how rigidly segmented Mesopotamian society was. Slaves were at the bottom, but could be freed in some cases. Men born free had the most rights, while women were subject to additional restrictions on what they could own and what freedoms they had.

Women, too, dealt with more restrictive laws. If a woman neglected and left her husband, she might be cast into the water; if a husband neglected his wife, his only punishment was that she could leave him. Men were also allowed to take another wife if their first wife bore them no children (though the law did stipulate that he must continue to care for her). But some protections for women did exist. If a wife became sick, the husband was forbidden from leaving her, for example; and if a man divorced his wife, she had rights to some of his property in some cases.

The Code assumes a person's innocence, for example, pending evidence to the contrary. The Mesopotamian legal system gave both accused and accuser a chance to state their cases before a judge.

https://www.discovermagazine.com/the-sciences/how-the-ancient-code-of-hammurabi-reveals-a-society-both-similar-and-alien

It says that everyone should expect access to justice, so it implies that all citizens are protected. Its punishments are very harsh, an eye for an eye. This strongly hints that Royal Prerogative is actually the most important principle and protecting subjects is quite secondary.

Nonetheless, it is a significant start towards offering equal human rights protections to all citizens.

Code Justinian 534 CE Eastern Roman Empire Byzantium

Code Napoleon 1804 Napoleonic reforms

The development of the Napoleonic Code was a fundamental change in the nature of the civil law legal system, making laws clearer and more accessible. It also superseded the former conflict between royal legislative power and, particularly in the final years before the Revolution, protests by judges representing views and privileges of the social classes to which they belonged. Such conflict led the Revolutionaries to take a negative view of judges making law.

This is reflected in the Napoleonic Code provision prohibiting judges from deciding a case by way of introducing a general rule (Article 5), since the creation of general rules is an exercise of legislative and not of judicial power. In theory, there is thus no case law in France. However, the courts still had to fill in the gaps in the laws and regulations and, indeed, were prohibited from refusing to do so (Article 4). Moreover, both the code and legislation have required judicial interpretation. Thus a vast body of case law has come into existence. There is no rule of stare decisis.

The preliminary article of the Code established certain important provisions regarding the rule of law. Laws could be applied only if they had been duly promulgated, and then only if they had been published officially (including provisions for publishing delays, given the means of communication available at the time). Thus, no secret laws were authorized. It prohibited ex post facto laws (i.e. laws that apply to events that occurred before their introduction). The code also prohibited judges from refusing justice on grounds of insufficiency of the law, thereby encouraging them to interpret the law. On the other hand, it prohibited judges from passing general judgements of a legislative value (see above). [8]

With regard to family, the Code established the supremacy of the husband over his wife and children, which was the general legal situation in Europe at the time. Women had even fewer rights than children. Divorce by mutual consent was abolished in 1804.[9]

The French Revolution's Declaration of the Rights of Man and of the Citizen declared that suspects were presumed to be innocent until they had been declared guilty by a court. A concern of Bonaparte's was the possibility of arbitrary arrest, or excessive remand (imprisonment prior to a trial). Bonaparte remarked that care should be taken to preserve personal freedoms, especially when the case was before the Imperial Court: "these courts would have a great strength, they should be prohibited from abusing this situation against weak citizens without connections." However, remand still was the usual procedure for defendants suspected of serious crimes such as murder.

https://en.wikipedia.org/wiki/Napoleonic\_Code

The biggest barrier to protecting marginalised or vulnerable people, is the plain refusal of privileged people to listen to their requests and pleas, let alone to provide care. That refusal to "swap chairs".

No-one is above the law, but the Royal Prerogative still applies!

Looking through history, we have found only limited protection of individual human rights.

In reading about altruism ideas in the ancient world, in all humility keep in mind how our Western society traditionally has tended to see these countries and cultures as inferior. Here, I am carefully placing them as ethically superior and worthy of us learning from them, if we can?

**Ancient Egypt** 

Possibly the earliest affirmation of the maxim of reciprocity, reflecting the ancient Egyptian goddess Ma'at, appears in the story of "The Eloquent Peasant", which dates to the Middle Kingdom (c. 2040–1650 BCE): "Now this is the command: Do to the doer to make him do."[9][10] This proverb embodies the do ut des

principle.[11] A Late Period (c. 664–323 BCE) papyrus contains an early negative affirmation of the Golden Rule: "That which you hate to be done to you, do not do to another."[12]

#### **Ancient Iran**

If we look back to ancient Iran, Zoroastrianism was the state religion approximately from 600 BCE to 650 CE. Its roots go back to at least 2000 BCE. Zoroastrian theology includes foremost the importance of following the Threefold Path of Asha revolving around Good Thoughts, Good Words, and Good Deeds.[40] There is also a heavy emphasis on spreading happiness, mostly through charity,[41] and respecting the spiritual equality and duty of both men and women.[42] Zoroastrianism's emphasis on the protection and veneration of nature and its elements has led some to proclaim it as the "world's first proponent of ecology

The core teachings of Zoroastrianism include:

Following the threefold path of Asha: Humata, Hūxta, Huvarshta (lit. 'good thoughts, good words, good deeds').[40]

Practicing charity to keep one's soul aligned with Asha and thus with spreading happiness.[41]

The spiritual equality and duty of men and women alike.[42]

#### Being good for the sake of goodness and without the hope of reward (altruism).

The Golden Rule is a well-entrenched concept in Zoroastrian ethics. It has been advocated and practiced throughout the history of its moral philosophy, a history imbued with remarkable verve and vigour, and conveying a sense of realism and high seriousness to moral life. The very idea of a radical distinction between the good and the bad is an essential source of this vigour. The goal of Zoroastrian ethics is summed up in the triad of "good thought, good word, good action," and constitutes the foundation for faith. These virtues imply thinking and speaking about the world as an ordered cosmos created by the Good Spirit, performing the acts required to maintain this sense of equilibrium, and conducting a virtuous life by implementing truth, purity, the right measure, and god-given order.



The Jewish faith built on these altruistic foundations (and later too the Islamic faith).

Hillel the Elder born 100 BCE dies 10 CE emphasised humility and respect and to turn the other cheek to offense.

Hillel encouraged that we should respect others the way that they wish to be respected by us. His work was influential in the Judaism faith.

## **Recent NZ History of Human Rights Protection**

Even in "modern" democracies, we see various forms of royal prerogative overriding the human rights of ordinary citizens and certainly of marginalised members of society, even where these human rights are protected by "black and white" legislation. We see this in the East and in the West. True democracy is a rare beast.

The quality of a democracy cannot be evaluated on paper, by reading legislation. What matters is what actually happens in Parliament and in the courts. Are they listening to the will of the people, are outcomes set by a privileged few, when push meets shove?

In recent NZ history, The Right Honourable Sir Piggy Muldoon used information supplied to him by members of the NZ Security Intelligence Service, to publicly humiliate Colin Moyle as a possible homosexual. At that time homosexual acts by men were a criminal offence. It was illegal for members of the NZSIS to spend their time surveilling NZ citizens, unless they were believed to be acting out treason or disposing of State secrets, which Colin Moyle did not even have access to at that time. It was illegal for such information to be passed on to the Prime Minister and illegal for the Prime Minister to use such information in such a way.

In the years since, the legislation has been tightened up and such activities turned into explicit crimes and Parliamentary oversight can now be more effective. Even so, no action was taken by the Speaker of Parliament to censure the Prime Minister for obviously unethical behaviour and breaching NZ's Constitution. Very low marks for NZ democracy.

A number of Aucklanders were prosecuted and jailed for child sexual abuse, on the basis of medical evidence that was later totally discredited. I am not aware that the earlier cases were revisited and the victims released from jail. In many of these cases, the affected mothers had established new intimate relationships, while their husbands were wrongly rotting in jail. Breaches of justice like this are impossible to redress and should never have happened in the first place. Although there is an obligation on the Prosecution Service to reopen cases like these, they only seem to do it when the public is watching. It appears that the pride of a few privileged individuals was more important than delivering justice. I forgot to mention that these men were in an ethnic minority generally with the lowest incomes in NZ and not well supported by the white majority.

NZ MMP (Multi Party Proportional Representation) election to Parliament has a 5% threshold for small parties. This figure was debated when the Act was first passed in Parliament. It stayed at 5% on the basis that this figure would be reconsidered after NZ had several years experience with MMP elections. This review has not occurred yet in about 20 years experience with MMP.

This has the effect that minorities below 5% find it quite difficult to gain any representation in Parliament.

People with mental health problems amount to about 25% of the population, well above the 5% MMP threshold. But their interests are poorly represented in Parliament. This shows up in funds allocated by

Parliament for mental health care have frequently been diverted by DHBs into other areas of medicine. For example, overheads have been charged solely to mental health budgets and the result is that a large part of the mental health budget effectively delivered value to obstetrics and gynaecology and the like. ????

As well as these procedural problems, their needs are poorly listened to by the public and by MPs. Their requests for help are not listened to, because they are easily dismissed as "other", as inferior members of society. As a result, our needs are poorly provided fo and children are poorly protected from abuse and maimed child development due to poor quality parenting and the impacts of poverty onto parents.

When marginalised people are left with no power, they cannot force people to listen. In our society, people with mental health problems are barely listened to. They have no power or agency at all.

One homeless man had observed that during the several years that he and other homeless men had been waiting for emergency accommodation, WINZ had arranged emergency accommodation for several women. On despairing of ever being heard at all, he took a shotgun and killed two WINZ workers. WINZ did listen and put security guards on the doors of WINZ offices, up and down NZ. (It is horrifying to note that WINZ paid the security staff less than the minimum wage, in breach of NZ legislation to protect workers from exploitation by powerful employers. It took two years for this breach to be rectified. This behaviour by WINZ is another example of Ruler's Prerogative coming before individual human rights protections.)

Most homeless people have serious mental health problems and have never been able to access Government medical mental health treatment. Their original mental health problems generally resulted from childhood abuse and neglect – where the Government and society failed totally to provide effective care and protection when they were vulnerable children. There, but for the Grace of God, go I. It is so easy to blame the victim, but at the material time they were babies, toddlers and small children. We must shoulder our own guilt and act positively to give care and protection.

WINZ never did arrange accommodation for that homeless man, he ended up in jail with a life sentence.

The whole episode shows the extreme reluctance of privileged people to listen to others less fortunate than themselves. That homeless man eventually obtained improvements for other people, but not for himself. It could be thought that he was being altruistic, beyond what others had given to him? It is a dire comment that two WINZ workers had to be killed, to obtain these improvements. It is a sad comment on our Government and courts.

The moral of the story is – don't be powerless.

Another useful comparison, is the protection of a rape accused and the protection given to the rape victim?

Consider the plight not just of adult women, but also children victims. Consider the chances of a successful prosecution, is it worth proceeding through a prosecution? When all of these factors are considered it can be thought that accused rapists are better protected than rape victims. Is this because judges see women as "other", thus refuse to understand the impact of rape onto women, or cannot understand these impacts, even if they tried.

Although it is never stated, it does appear that there is a hierarchy of human rights protection. When we look at the dates at which different aspects of human existence received human rights protection. Generally heterosexual men gained protections first. Slowly, over hundreds of years, protections were extended to women, the homosexual men, other racial groups. Looking at these dates shows how strongly privileged groups have fought, to refuse human rights protections to people other than themselves.

Going back to the Russian soldiers captured as prisoners of war in Ukraine. They were compulsorily conscripted. They were at the very bottom of the hierarchy of human rights protection. If sent back to Russia, they could possibly be more vulnerable than being a prisoner of war in Ukraine. Some had applied for asylum on that basis.

By contrast, president trump of USA was known to be a draft dodger, by travelling to Canada through the time that he was subject to draft. He didn't see any need to comply and wasn't embarrassed about his behaviours.

A lawyer entering Mt Eden prison to see a client, was strip searched without a court warrant. He sued the prison authorities and was quickly awarded \$10,000 compensation.

By comparison, when Maori were held at gunpoint by police, during the Wairarapa Police Raids, this was found to be illegal. The police had hidden their identity badges and refused to identify themselves. But no compensation was awarded to the many Maori who were affected and affected for longer periods of time and affected in a much more life threatening way. White Privilege with icing on top, alas. Legal Fragility – the judges just did not take Maori grievances seriously, compared to their own egos.

When a western European man saw Russian men getting drunk and leaving most of the work to the women, he was told by one of the women "We know that if there is another war, they will be quickly conscripted and sent away. I know how much hope they have. They will be casually sent to their deaths by our government. I want my son to enjoy every moment he has on this Earth, in any way he wants to enjoy it. "The Western European man was stunned and silent.

For all the talk of Male Privilege, not many women would be willing to swap places for a few moments, let alone to be permanently in that situation. In all humility, we do need to face all of these facets of our lives and make the best decisions that we can, in this changing world. We have to face those situations in which we take advantage of other people, even where we try to think it isn't important (to us).

## **Privilege in NZ Today**

A privileged person can easily refuse to listen to a marginalised, disempowered, vulnerable person. On the contrary, it takes willingness and effort to actually listen. And for what gain – none at all? ? ??

What credibility do they have?

What could I learn from them, when they are a failure in every sense?

If I have a warm house, what can I learn from a person who is forced to sleep under motorway bridges, in cemeteries, in shop doorways, when it is raining, cold and windy?

That is exactly how they have built up their influence, their power, their privilege - by NOT listening to "those" who are weak or vulnerable.

Blaming victims works very well, in the short term, in our world. Blaming people who failed to protect themselves when they were babies, or toddlers or small children..... or were forced to face gunmen with no arms......

But this is not the face of altruism and open hearted human rights protection. Can we remember - there but for the Grace of God, go I.

A wise person can learn from a fool, but a fool can't learn from a wise person.

A fool can refuse to listen, because in their cultural superiority they are not aware that the barrier to listening lies in their own head. Perhaps, behind their own eyes?

Frank Lowie, the businessman who built up the Westfield Shopping Centres, said that he found that it was so much easier to make deals with fellow Jews. In essence, people who were culturally very similar to him. He approached every business deal as if it might be his last.

It was only in his seventies that he discovered he did not have to do business like that. He grew up as a young teenager, in the Warsaw ghetto, under ever present threat of being arbitrarily killed for no reason.

Please think through your own culture and choose how you wish to live your life. Exercise your own agency, don't be controlled by the facts of your history.

## I will be prejudiced just this once (once doesn't really matter)

When I choose to give a rental tenancy to a sensible person, who has a job and stable life, over a person with mental health problems, I am just being prejudiced this once.

Well actually, there were lots of "just one time". But it doesn't add up to anything, in my life.

But that person has just experienced prejudice in obtaining accommodation, in obtaining a job, in getting a bank loan. It wasn't just once, but at every step of the way. From less money in their pocket, they have to apply for more house tenancies, to apply for more jobs, to be treated as "other" at the local church.

What didn't add up to anything, in the eyes of the privileged person, added up every step of the way for the marginalised person. It didn't just add up in the dis-affirmation of feelings, the little bit of money in their pocket disappeared extra quickly for transport and other costs to make applications.

If we care to see, the costs of prejudice add painfully and it should be easy to see why suicide becomes attractive and protective. This is what our "survival of the fittest" society is all about. We can pray wearing a suit, forgetting that - there but There for the Grace of God go I.

If you choose to listen - you can exercise your agency to make a better world for everyone. Who knows, one day it might be you, that is not being listened to and who is sliding down toward oblivion. For whom death is now attractive.

Dehumanising the "other" is sliding gently and without brakes towards genocide, if our lives become more difficult for some reason.

We must willingly accept that the same standards of behaviour should apply to ourself, as to others.

Even more important than applying this to individuals, we must apply the same standards to all country's actions. Given the issues of many cultures, it is very difficult to do this. Peace can only be safe, when we are doing this. An essential feature is respect for human rights, over countries freedom to break rules because they feel fear.

Ruler's Prerogative doesn't have to be visible in legislation to happen. It is the actual behaviours that matter, in courts and Parliaments. If it is present in judge's behaviour, then it is a social problem. If it is in Government's behaviour, then it is a problem.

Although how marginalised people are treated and Ruler's Prerogative are at the opposite ends of the privilege spectrum, comparing them gives a clear measure of the altruism of a society.

#### White Fragility in NZ Today

It is difficult to accept that my success is partly my own work and partly due to privileges of who my parents were. Of course I chose my parents well. That perhaps I have treated others with cruelty and insensitivity, that I was to some degree - the Bad Guy. Even if it was completely "legal" at the time. I didn't feel the "others" pain. I left them to it. I turned a deaf ear and a blind eye.

Jeremiah 5:21 Hear now this, O foolish people, and without understanding; which have eyes, and see not; which have ears, and hear not.

There are none so blind, as will not see.

I am a white person in NZ. Whether I like it or not, I have benefitted from the unethical behaviour of my ancestors. Behaviour that today would surely be rewarded with long jail sentences. So how can I say forget that, it is in the past and sit quietly on the benefits. Then and now, the law is quite clear, a thief cannot gain ownership of what they stole. To steal land from under their feet.

At that time, theft was a crime. Murder to commit theft was at the very high end of murder as a crime. It is no different today. There are no extenuating circumstances, on the contrary. Settler colonialism crimes were and still are crimes. To see Maori as subhuman was only a convenient delusion, by people with murder in their hearts and theft in their mind. To further murder to cover their tracks makes it only worse....

So why should I hope to be let off lightly in this clear situation?

If I wish to face the visceral reality of what my ancestors did, in fairly recent history, surely I have to face the unethical reality of these actions and seek reconciliation from the victims. It is not enough for me to blame the victims, for being victims. As yet, we haven't satisfactorily reconciled for these heinous crimes.

White privilege is one issue.

Another issue is White Fragility - the unwillingness to face and address the crimes of white privilege in NZ.

The refusal to acknowledge it and then to act to seek reconciliation from the victims of these widespread crimes.

In the same way there is Able Fragility - the unwillingness to face the impacts of able-ism. Ditto wealth....

## When You Feel the Other is Not Listening Not Understanding

In this heading, it was somewhat ambiguous as to whether the word "other" had the meaning of the person you are talking to, or "other" in the sense of very different culture from myself, probably inferior and possibly not really human at all?

As well as me considering the person I am with as "other", they may be considering me as "other"?

That is the question we need to ask ourself, when our self-advocacy just doesn't seem to be getting anywhere. Maybe the person we are with is looking on me as "other", in the sense of very different culture from themself and possibly I am not really human? (I know I am human, but they may not know I am human???)

When we can sense that we are making no progress at all, it almost certainly is not worth proceeding. We are more likely to do further harm to the relationship and there is little prospect of being able to make an improvement. Withdraw to a safe distance.

Maybe we can recover our humanity by using small talk to link us back into their human world, but this might only be a slim hope. If that doesn't work, then you need to call in the cavalry (if you have access to them).

Our remaining options are to find an advocate to speak for us, who is not seen as "other", or an ally for the same reason. Community Organising Te Ohu provides a framework for linking together many marginalised groups. When one is dehumanised to "other", likely some other marginalised people are still respected as human. They can be effective as advocates or allies. When we are marginalised, it is valuable to find what allies that we can and make good use of them.

This powerlessness reflect that MMP voting system in NZ only gives Party Seats to parties with at least 5% of the total vote. At the time that MMP was introduced this figure was strenuously argued and the larger parties refused to support any figure less than 5%. It was stated that this figure could be reviewed when there was experience with MMP voting. But this hasn't happened yet.

This process of feeling the other person as subhuman "other" isn't just an issue between able people to disabled people, it applies maybe even more between groups of disabled people. This is a serious barrier to

us working together, to submit joint proposals to Government. We have to put in the effort to understand each other and our respective situations, so that we can advocate more effectively to Government.

## Outsider / "Other"

It is natural for us to find relationships easier within our own culture. Though this is forgetting that even within our own culture, there are still lots of differences, just that we are more familiar with them.

That is where host skills show their value. Can we welcome someone that we are much less familiar with and allow them to feel comfortable, safe even, within our spaces?

Frank Lowie said he found it so much easier to do business with fellow Jews. ?????

In times of greater survival pressure, suspicion of outsiders served an important evolutionary advantage. But it was also important to not inbreed and that was also important in an evolutionary sense, to survive. Delicate compromise. Today those issues remain, but we have more freedom to choose how we want to behave.

Living with such great suspicion of people that we are unfamiliar with is cruel and destructive to marginalised groups of people.

The word "other" has many meanings. It is easy to slip, without noticing, from one meaning to another, from an innocent meaning to totally dehumanised meaning.

If we notice ourselves losing empathy or sympathy to someone who is different in some way..... sniff, sniff sneeze do I feel a Genocide coming on?

Genocides explode like a viral infection, when there is uncombusted fuel of unreconciled hatred lying around. Intergenerational trauma must be addressed constructively.

Stop – is this where I want to go?

Remember those young Serbian men who were swept along in the hatred and did rapes and murders in cold blood.

Lets not pass on such unreconciled hatreds to our children.

I have pulled out another – swap seats. I need help...

There, but for the Grace of God, go I.

#### **Genocide in Recent History**

https://en.wikipedia.org/wiki/Genocide

Analysis of genocide before World War I is the result of modern studies applying objectivity and fact.

While the concept of genocide was formulated by Raphael Lemkin in the mid-20th century, the expansion of various European colonial powers such as the British and Spanish empires, and the subsequent establishment of colonies on indigenous territory frequently involved acts of genocidal violence against indigenous groups in the Americas, Australia, Africa, and Asia.[9] According to Lemkin, colonization was in itself "intrinsically genocidal", and he saw this genocide as a two-stage process, the first being the destruction of the indigenous population's way of life. In the second stage, the newcomers impose their way of life on the indigenous group.[10][11] According to David Maybury-Lewis, imperial and colonial forms of genocide are enacted in two main ways, either through the deliberate clearing of territories of their original inhabitants in order to make them exploitable for purposes of resource extraction or colonial settlements, or through enlisting indigenous peoples as forced laborers in colonial or imperialist projects of resource extraction

In 1915, one year after the beginning of World War I, the concept of crimes against humanity was introduced into international relations for the first time when the Allies of World War I sent a letter to the government of the Ottoman Empire, a member of the Central Powers, protesting massacres that were taking place within the empire, among them the Armenian genocide, the Assyrian genocide, the Greek genocide, and the Great Famine of Mount Lebanon.[14] The Holocaust, the Nazi genocide of 6 million European Jews during World War II, is the most studied[15] and a prototype of genocide.

During the Cold War era, mass atrocities were committed by both anti-communist/capitalist[22][23] and Communist regimes,[24] among them the 1965–66 Indonesian mass killings and the Cambodian genocide.[25] The Rwandan genocide gave an extra impetus to genocide studies in the 1990s.

#### **Bosnia and Herzegovina**

In July 1995, Serbian forces killed more than 8,000[28][29][30] Bosniaks (Bosnian Muslims), mainly men and boys, both in and around the town of Srebrenica during the Bosnian War.[31][32] The killing was perpetrated by units of the Army of Republika Srpska (VRS) which were under the command of General Ratko Mladić.

In 2010, Vujadin Popović, Lieutenant Colonel and the Chief of Security of the Drina Corps of the Bosnian Serb Army, and Ljubiša Beara, Colonel and Chief of Security of the same army, were convicted of genocide, extermination, murder and persecution by the ICTY for their role in the Srebrenica massacre and were each sentenced to life in prison.[45][46][47][48] In 2016 and 2017, Radovan Karadžić[49] and Ratko Mladić were sentenced for genocide

#### Rwanda

the genocide that occurred there during April and May 1994, commencing on 6 April. at least 800,000 people were killed

#### Cambodia

The Khmer Rouge, led by Pol Pot, Ta Mok, and other leaders, organized the mass killing of ideologically suspect groups, ethnic minorities such as ethnic Vietnamese, Chinese (or Sino-Khmers), Chams, and Thais, former civil servants, former government soldiers, Buddhist monks, secular intellectuals and professionals, and former city dwellers. Khmer Rouge cadres defeated in factional struggles were also liquidated in purges. Man-made famine and slave labor resulted in many hundreds of thousands of deaths.[57] Craig Etcheson suggested that the death toll was between 2 and 2.5 million, with a "most likely" figure of 2.2 million. After five years of researching 20,000 grave sites, he concluded that "these mass graves contain the remains of 1,386,734 victims of execution."[58] Some scholars argued that the Khmer Rouge were not racist and had no intention of exterminating ethnic minorities or the Cambodian people; in this view, their brutality was the product of an extreme version of communist ideology.

#### Darfur, Sudan

n 2013 the United Nations (UN) estimated that up to 300,000 people had been killed during the genocide. Over 3 million lives are heavily impacted by the conflict.

## Ten stages of Genocide

https://en.wikipedia.org/wiki/Ten\_stages\_of\_genocide

#	Stage	Characteristics	Preventive measures
1	Classification	People are divided into "them and us".	"The main preventive measure at this early stage is to develop universalistic institutions that transcend divisions."
2	Symbolization	"When combined with hatred, symbols may be forced upon unwilling members of pariah groups"	"To combat symbolization, hate symbols can be legally forbidden as can hate speech."
3	Discrimination	"Law or cultural power excludes groups from full civil rights: segregation or apartheid laws, denial of voting rights".	"Pass and enforce laws prohibiting discrimination. Full citizenship and voting rights for all groups."
4	Dehumanization	"One group denies the humanity of the other group. Members of it are equated with animals, vermin, insects, or diseases."	"Local and international leaders should condemn the use of hate speech and make it culturally unacceptable. Leaders who incite genocide should be banned from international travel and have their foreign finances frozen."
5	Organization	"Genocide is always organized Special army units or militias are often trained and	"The U.N. should impose arms embargoes on governments and citizens of countries involved in genocidal massacres, and create

		armed"	commissions to investigate violations."
6	Polarization	"Hate groups broadcast polarizing propaganda"	"Prevention may mean security protection for moderate leaders or assistance to human rights groups Coups d'état by extremists should be opposed by international sanctions."
7	Preparation	"Mass killing is planned. Victims are identified and separated because of their ethnic or religious identity"	"At this stage, a Genocide Emergency must be declared. Full diplomatic pressure by regional organizations must be invoked, including preparation to intervene to prevent genocide."
8	Persecution	"Expropriation, forced displacement, ghettos, concentration camps".	"Direct assistance to victim groups, targeted sanctions against persecutors, mobilization of humanitarian assistance or intervention, protection of refugees."
9	Extermination	"It is 'extermination' to the killers because they do not believe their victims to be fully human".	"At this stage, only rapid and overwhelming armed intervention can stop genocide. Real safe areas or refugee escape corridors should be established with heavily armed international protection."
10	Denial	"The perpetrators deny that they committed any crimes"	"The response to denial is punishment by an international tribunal or national courts."

# **Analysis**

Other genocide scholars have focused on the cultural and political conditions that lead to genocide. Sociologist Helen Fein showed that pre-existing antisemitism was correlated with the percentage of Jews killed in European countries during the Holocaust. Political scientists such as Dr. Barbara Harff have identified political characteristics of states that statistically correlate with risk of genocide: prior genocides with impunity, political upheaval, ethnic minority rule, exclusionary ideology, autocracy, closed borders, and massive violations of human rights. [4]

Stanton's model places the risk factors in Harff's analysis into a processual structure. For instance:

- Political instability is characteristic of what Leo Kuper<sup>[5]</sup> called "divided societies" with deep rifts, as in *classification*.
- Naming and identifying members of the group occurs through symbolization.
- Groups targeted by the state are victims of discrimination.
- An exclusionary ideology is central to dehumanization.
- Autocratic regimes foster the organization of hate groups.
- An ethnically polarized elite is characteristic of polarization.

- Lack of openness to trade and other influences from outside a state's borders is characteristic
  of preparation.
- Massive violations of human rights are examples of persecution.
- Extermination of the group in whole or in part legally constitutes Genocide.
- Impunity after previous genocides is evidence of denial.

Stanton has suggested that "ultimately, the best antidote to genocide is popular education and the development of social and cultural tolerance for diversity

The reasons given above show why human rights protections are critical, to prevent privileged groups using dehumanising tactics onto marginalised groups.

## **Bringing Up Our Children**

In the privacy of our home, what we say to our children brings out the values of our society and the conflicted present in our society. We are bringing up our children to survive and we hope, thrive.

But the conflict of bringing up our children to be willing soldiers, goes quite against our desire for them to enjoy a good life. Do we gloss over these issues? Do we express our own discomfort?

Bringing up our boy children and girl children again brings out a different set of conflicts of interest.

Although The Code of Hammurabi said to expect justice, do we explain that justice is an ideal that some people are destined to see only the breach?

For us to act, we must face our discomfort.

#### Leave No-one Behind

To act on Leave No-one Behind, we need to listen openly and sensitively and make balanced decisions. We need to be able to apply respectful, appropriate standards fairly.

It is only through careful listening and understanding, that he can handle multiple problems and intersections fairly.

It is only through respecting other cultures, that we can listen and understand.

## Appendix K DWF Team Building

We are a group of women from many backgrounds. We have a wide range of knowledge and experiences. We have access to different abilities and resources. We probably have a wide range of values.

We can achieve the most, if we can bring together our strengths and cover for each of our weaknesses. To do this, we have to know each other well. Besides, the better we know each other, the more we can support each other and enjoy each other's company.

As part of our 3-weekly meetings, we will devote a few minutes to the following team building activities:

Consciousness raising, looking at the history of women's movement and where to from here.

Opening up to each other. This will not be under any pressure. If not comfortable, please feel free to stay quiet. If anyone wishes, they can discuss privately with the leader or any other group members that they choose. People who are in more marginalised situations will probably wish to proceed slowly and cautiously. Learning to support each other is critical to our success.

Sharing the history of DWF, what it is doing and where we hope it will go. Through this, we hope to invite new members to take active part.

Discussing advocacy, ally-ship, mediation, negotiation, human rights activism in general.

In some situations, we will learn about issues through the use of safe proxies. For example, we can more easily learn about the issues underlying prejudice, by discussing racial prejudice within USA. When we are fairly comfortable discussing these very challenging issues, we can then start discussing racial prejudice and gender prejudice in NZ. Then we will be better placed to support each other and to handle the guilt and pain that will be opened up.

Discuss the meeting styles used by various types of organisations, so that we can use these styles when appropriate. Examples are:

Social organisations

Co-counselling movement

**Businesses** 

Top down eg military or kingdoms

Society of Friends, Bahai, Buddhist

Learn about advocacy issues, ally-ship, negotiating, mediation and political action.

Embrace failure and learn from it

Speakouts by individual members.

It is not intended to put pressure on members to come to each meeting. Meeting materials will be saved and made available afterwards. (If there any privacy issues arise, deletions would be made to protect members.) Background books and materials are also available, if anyone wishes to study topics further.

Staff of the Ministry of Women's Affairs suggested to the IWC meeting, that politicians listened more to larger groups, especially submissions signed off by several organisations with large memberships. When disparate groups can reach consensus, it leaves less requirement for the politicians to divide a limited total budget between affected groups. Also the division is more likely to be equitable, if it was agreed to by all of the affected participants.

Te Ohu Community Organisers also make the same recommendation, for the same reason.

One of the women in the audience commented that that would be very unlikely that the various disability groups could agree on a joint submission, as many of the groups of disabled women would not cooperate with each other. Unfortunately this comment was in line with experience in the last few years.

This may be seen as a challenge – if we want to have more impact with politicians and Government, we have to cooperate and work between ourselves to form a workable consensus and unified submissions.

This will be a huge challenge, as our mutual understanding is somewhat poor. We need to spend more time to patiently understand each other's needs and situations. It does take considerable time to bring to fruition, as there are many different situations to learn about. But the potential rewards are great, so we must rise up to face these communication barriers.

As well as mutual understanding being difficult, perhaps an even bigger challenge is limited energy, limited understanding of disability issues, limited financial resources and apathy among our members.

We have struggled for many years against these limitations and have never achieved critical mass. The generous support from ZZZZ temporarily overcame these problems, but now we have the challenge to sustain the momentum achieved through the time of the Conference. So far, we have barely been able to maintain momentum.